

Summer 2009

# Culture Care Beliefs, Meanings and Practices Related to Health and Well-Being of South Sudanese "Lost Boy and Lost Girl" Refugees

Margaret Bowles

Follow this and additional works at: <https://dsc.duq.edu/etd>

---

## Recommended Citation

Bowles, M. (2009). Culture Care Beliefs, Meanings and Practices Related to Health and Well-Being of South Sudanese "Lost Boy and Lost Girl" Refugees (Doctoral dissertation, Duquesne University). Retrieved from <https://dsc.duq.edu/etd/345>

This Immediate Access is brought to you for free and open access by Duquesne Scholarship Collection. It has been accepted for inclusion in Electronic Theses and Dissertations by an authorized administrator of Duquesne Scholarship Collection. For more information, please contact [phillips@duq.edu](mailto:phillips@duq.edu).

CULTURE CARE BELIEFS, MEANINGS AND PRACTICES RELATED  
TO HEALTH AND WELL-BEING OF SOUTH SUDANESE  
“LOST BOY AND LOST GIRL” REFUGEES

A Dissertation

Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for  
the degree of Doctor of Philosophy

By

Margaret Elizabeth Bowles

August 2009

Copyright by  
Margaret Elizabeth Bowles

2009



DUQUESNE  
UNIVERSITY  
SCHOOL OF NURSING

PhD PROGRAM

## APPROVAL OF FINAL DEFENSE OF DISSERTATION

**STUDENT:** Margaret Bowles

**DATE OF ADMISSION:** Fall 2003

**DISSERTATION TITLE:** Culture Care Beliefs, Meanings and Practices Related to Health and Well-Being of South Sudanese "Lost Boy and Lost Girl" Refugees

---

### DISSERTATION COMMITTEE:

	<u>Type name below</u>	<u>Signature</u>	<u>Date</u>
<b>Dissertation Chair:</b>	Rick Zoucha, PhD, APRN-BC, CTN	_____	_____
<b>Internal Member:</b>	Shirley Smith, PhD, RN, CRNP	_____	_____
<b>External Member:</b>	Jok Madut Jok, PhD	_____	_____
<b>Ad hoc, if applicable:</b>		_____	_____

Approved by Dissertation Chair and Committee

---

Joan Such Lockhart, PhD, RN, CORLN, AOCN<sup>®</sup>, CNE, FAAN  
Professor & Associate Dean for Academic Affairs

---

Date

## ABSTRACT

### CULTURE CARE BELIEFS, MEANINGS AND PRACTICES RELATED TO HEALTH AND WELL-BEING OF SOUTH SUDANESE “LOST BOY AND LOST GIRL” REFUGEES

By

Margaret Elizabeth Bowles

August, 2009

Dissertation Supervised by Professor Rick Zoucha, PhD, APRN-BC, CTN

The purpose of this ethnonursing study was to describe, analyze and interpret the culture care beliefs, meanings and practices related to health and well-being of South Sudanese “Lost Boy and Lost Girls” following resettlement in the United States.

Leininger’s theory of culture care diversity and universality and the ethnonursing method provided the organizing framework for studying the domain of inquiry. Interviews were conducted with nineteen general informants and ten key informants, all who lived in the Midwest United States. Extensive analysis of digitally recorded interviews together with the researcher’s participant observations and field notes revealed nine data categories and five patterns from which three main themes emerged. The themes were (a) spiritual care, grounded in a belief in the strength and wisdom of one God, is health promoting and illness preventing; (b) contributing to and meeting the expectations of the community are necessary for health and well-being; and (c) the conflicting expectations of two cultures

are affecting health and well-being. The findings of this study provide a framework from which to develop culturally congruent care for the “Lost Boys and Girls.” Implications and recommendations for nursing theory, practice, education, and research are offered.

## DEDICATION

This dissertation is dedicated to my husband Robin, and our children, Colin and Anne, who have supported me in so many ways over the past six years of doctoral studies. I couldn't have done it without your love, support and encouragement.

I also dedicate this dissertation to my mother Jessie Herreshoff, who led the way by being the first person in our family to go to college, and the first to earn a PhD. She consistently told me I could do it. It is also dedicated to the memory of my father, Archie Edwards, who believed I could do no wrong.

## ACKNOWLEDGMENT

My sincere gratitude goes to Dr. Rick Zoucha, my committee chair, for helping me in countless ways through the sharing of his wisdom, knowledge, humor, and continuous support. I would also like to thank my dissertation committee members Dr. Shirley Powe Smith and Dr. Jok Madut Jok for supporting me through this process with their insightful comments and thoughtful advice.

Special thanks to the Kappa Epsilon Chapter of Sigma Theta Tau for awarding me the 2008 Research Award that assisted with the costs of this study, and to the Transcultural Nursing Society for awarding me the 2003 Graduate Research Award which assisted with the costs of the Mini-Study which provided the foundation for this study.



## TABLE OF CONTENTS

	Page
Abstract .....	iv
Dedication .....	vi
Acknowledgement .....	vii
<b>1 Introduction</b>	
1.1 The “Lost Boys and Lost Girls of Sudan” .....	1
1.2 Background.....	4
1.3 Domain of Inquiry and Rationale .....	5
1.4 Purpose and Goals.....	5
1.5 Research Questions .....	6
1.6 Significance to Nursing.....	7
1.7 Orientational Definitions .....	12
1.8 Assumptions.....	16
1.9 Summary .....	17
<b>2 Review of the Literature</b>	
2.1 Sudan .....	18
2.2 Historical Overview .....	21
2.3 Ethnohistory .....	24
2.4 The People and Languages .....	26
2.5 Worldview .....	27
2.6 Religion.....	28
2.7 Education .....	30

2.8 Political and Legal Systems .....	32
2.9 Economics .....	33
2.10 Kinship Structure .....	34
2.11 Cultural Values and Lifeways.....	36
2.12 Refugee Camps .....	38
2.13 Health and Well-being of Lost Boys and Lost Girls in Refugee Camps .....	40
2.14 Health and Well-being of Lost Boys and Lost Girls in Resettlement .....	44
2.15 Synthesis of the Literature .....	48
2.16 Theoretical Framework Orientation Using Leininger's Theory of Culture Care Diversity and Universality .....	49
2.17 Summary .....	52

### **3 Methodology**

3.1 Ethnonursing Method .....	54
3.2 Mini Study .....	55
3.3 Context of the Study .....	57
3.4 Entry into the Community .....	57
3.5 Informants.....	59
3.6 Data Collection .....	60
3.7 Human Subjects and Ethical Considerations.....	63
3.8 Data Analysis.....	64
3.9 Summary.....	65

### **4 Results and Findings**

4.1 Introduction.....	67
-----------------------	----

4.2 Presentation of Categories .....	69
4.3 Environmental Factors .....	70
4.4 Relationship Between Environmental Factors and Health and Well-being .....	75
4.5 Kinship and Social Factors .....	77
4.6 Cultural Values and Lifeways.....	85
4.7 Religion and Spiritual Factors .....	99
4.8 Economic Factors .....	101
4.9 Relationship between Economic Factors and Health and Well-being .....	103
4.10 Educational Factors.....	106
4.11 Relationship between Educational Factors and Health and Well-being .....	109
4.12 Political and Legal Factors .....	110
4.13 Technological Factors.....	118
4.14 Meaning of Health and Well-Being.....	120
4.15 Maintaining Health and Preventing Illness.....	124
4.16 Health-Seeking Behaviors .....	132
4.17 Barriers to Care .....	134
4.18 Traditional Healing Practices.....	140
4.19 Experiences with Professional Care .....	141
4.20 Presentation of Patterns and Themes .....	144
4.21 Summary .....	147

## **5 Discussion of Findings**

5.1 Introduction .....	148
5.2 Presentation of Themes .....	150

5.3 Discussion of Culturally Congruent Nursing Care.....	167
5.4 Nursing Implications .....	175
5.5 Conclusion .....	179
References .....	181
Appendix 1 .....	189
Appendix 2 .....	190
Appendix 3 .....	192
Appendix 4 .....	194
Appendix 5 .....	195

# Chapter 1

## Introduction

### 1.1 The “Lost Boys and Girls” of Sudan

Before delving into the culture care beliefs of South Sudanese “Lost Boy and Lost Girl” refugees, it is necessary to ask, “Who are the “Lost Boys and Girls” of Sudan? How did they come to be called “lost boys and girls”, and what is the significance of that name? Initially, there was no reference to “lost girls”, since very few girls fled Sudan without their families. Differing versions of the origin of the term “lost boys” have appeared in the literature and popular press. Informants in this study offered a variety of ideas on the origin of the name; the most common being that they were initially identified as “lost boys” by journalists who first covered the story of their flight from Sudan to Ethiopia and by the international aid workers who provided for them on arrival in Ethiopia. It was hoped that their identification as “lost boys” would result in the funding and resources which the relief agencies required to provide for their safety and care. An informant in this study stressed that United Nations (UN) aid workers and the case workers at Kakuma also referred to them as “lost boys” to identify which boys had been unsuccessful in tracing their parents and family. According to this informant, only those who could prove they were “lost boys” were chosen to come to the United States.

Human Rights Watch (HRW) documented recruitment of unaccompanied boys from refugee camps in Ethiopia by the Sudanese People's Liberation Army. HRW/Africa (1994, p.6) reported that the SPLA "engaged in recruitment of boy soldiers and in the separation of children from their families for this purpose. Since 1987 the SPLA has maintained large camps of boys separate from their relatives and tribes in refugee camps in Ethiopia and in southern Sudan. From these camps the SPLA has drawn fresh recruits as needed, regardless of the age of the boys." Several informants in this study described their experience as child soldiers between the ages of 10 and 14. One informant stated that the name "lost boy" was initially given to those boys who served in the *jeish ahmer*, or "Red Army", a military unit made up of "lost boys". This informant stated that he made the choice to join the Red Army when he was 10, while at Pignudo Refugee camp in Ethiopia.

In a study analyzing group care arrangements and the fostering program for the unaccompanied minors provided by Save the Children Sweden at Pignudo and Kakuma, it was noted that no one, clear explanation emerged for how the lost boys came to be separated from their families. However, it was concluded that "the majority left their families in an organized manner, motivated, it seems, by the SPLM's wish to secure an educated cadre of citizens and to provide a future source of manpower (Derib, 2002, p.2).

While all the factors leading to the exodus of the lost boys from South Sudan may never be known, as a group they have found a sense of purpose and meaning for their lives which may be expressed through the telling of their story. The young men who participated in this study, all young adults now, expressed pride in being among the "Lost Boys of Sudan". A key informant noted, "We don't feel like humiliated, when

somebody call you lost boy, because when somebody call you with that name, it reminds you how that name came about, or how was the condition by then. How you got that name reminds you about the history, what was going on before then. And so although some of us are married and we are now adult, but still that name can still exist. I hope it will still exist then for quite a number of years, because it traces us back to our history or to our back roots and then how we got here too”.

Very few girls were at Pignudo or Kakuma refugee camps, as it was considered best for girls to remain among family for their well-being and safety. Those few who made their way to Kakuma often did so with the support of their families, who had hopes that they would have greater opportunity for a secure future in the United States. At Kakuma, most girls were placed with foster families according to tradition, again for their safety and protection. Children who were living with foster families failed to meet the strict criteria for “unaccompanied minor”, and as a result were not included among those who were accepted for resettlement in the U.S. Aid and relief workers, as well as members of the Press, began to speak of discrimination that was barring girls from the opportunity the boys had to resettle in the United States. Rather than speak of the “lost boys”, the new, more inclusive and politically correct term became the “lost boys and girls of Sudan”. It is important to note that the life experiences of the lost girls who resettled in the United States differ significantly from those of the boys. This is not to say that they have not suffered; they have. However, the majority of girls remained a part of their family unit, and continued to receive guidance from family and kin, throughout their lives in Africa.

## 1.2 Background

Sudan has been ravaged by civil war with brief interruptions since 1955, the longest ongoing civil war in the world. The war pitted government forces of North Sudan, which is predominately Arab and Islamic, against the peoples of South Sudan, predominately black Africans who adhere to indigenous beliefs and/or are Christian. While a Comprehensive Peace Agreement formally ending the war was signed in 2005, the agreement is showing signs of strain, and the potential for further conflict remains. The causes of the conflict are complex and include racial, cultural, religious, economic, and political differences. Crimes have been committed by parties on all sides of the conflict, and civilians are the ones who suffered most, through the enslavement of women and children, the conscription of child soldiers, and the raiding and pillaging of villages which often resulted in starvation and death (Bolea, Grant, Burgess, & Plasa, 2003; Duany, 2003; Jok, 2001; Radda Barnen, 1994; United States Committee For Refugees, 1999; Zutt, 1994).

According to the United States Department of State Bureau of Population, Refugees, and Migration (2001), approximately 3,800 young South Sudanese refugees, commonly referred to as the Lost Boys and Girls of Sudan, were resettled in the United States from Kakuma refugee camp in Kenya between November 2000 and September 2001. Left behind at Kakuma to lead a very different life were nearly 5000 of their peers (Schechter, 2004). The lost boys and lost girls (LBLG), the majority of who were children and young adults between the ages of 16 and 24 at the time of their resettlement, identify themselves as Dinka and Nuer people of South Sudan. Eighty-nine lost girls who were found to meet the resettlement criteria, along with 3,276 lost boys, were admitted to



the United States as refugees without parents, minimal understanding of life in the United States, and no knowledge of the American health care system.

### 1.3 Domain of Inquiry and Rationale

The domain of inquiry for this study was the culture care beliefs, meanings, and practices related to health and well-being of South Sudanese LBLG refugees within the context of their new home in the midwestern United States. There is currently no published nursing research about the culture care beliefs, meanings, and practices of the LBLG. Nursing research focused on this domain was essential to increase knowledge and understanding of culturally influenced health care beliefs and practices so that nurses can minimize the special health risks of the LBLG and identify and implement culturally congruent caring practices.

### 1.4 Purpose and Goals

The purpose of this ethnonursing study was to describe, analyze and interpret the culture care beliefs, meanings and practices related to health and well-being of South Sudanese LBLG who were resettled in the United States beginning in November 2000. The goals of this study were to (a) utilize participant observation and semi-structured interviews to elicit emic data that will provide in-depth understanding of health beliefs and practices of South Sudanese LBLG refugees; (b) identify how worldview and cultural and social structure dimensions such as kinship, religious, political, legal, economic, educational, and technological factors influence the LBLGs' generic and professional care beliefs and practices; (c) discover or describe culture care knowledge including

traditional generic (folk) and professional caring practices that promote the health and well-being of LBLG; and (d) explore ways to integrate both types of care into the planning and implementation of culturally congruent care within the South Sudanese LBLG communities throughout the United States. It is predicted that health care providers and the LBLG will benefit through increased trust, understanding, and satisfaction with the provision of culturally sensitive care leading to improved health and well-being.

### 1.5 Research Questions

The following research questions, developed within the framework of the theory of culture care diversity and universality (Leininger & McFarland, 2006) served as a general guide for the discovery of culture care meanings, beliefs, and practices related to the health and well-being of South Sudanese LBLG refugees.

1. What are the culture care beliefs, meanings, and practices related to the health and well-being of South Sudanese LBLG refugees?

2. How have the worldview, cultural and social structure dimensions, environmental context, and ethnohistory influenced the health and well-being of South Sudanese LBLG refugees?

3. What are the generic (folk) and professional care beliefs, meanings, and practices of South Sudanese LBLG refugees?

4. What are the specific nursing decisions and actions that will enhance the health and well-being of South Sudanese LBLG refugees through the provision of culturally congruent care?

## 1.6 Significance to Nursing

This study was conceptualized within Leininger's theory of culture care diversity and universality (Leininger, 1997a). Understanding clients' cultural beliefs related to health and well-being is a core value in nursing; a prerequisite to planning culturally congruent care (DeSantis, 1997; Giger & Davidhizar, 2004; Leininger, 1991; Leininger & McFarland, 2006; Lipson, 1992). Leininger (1991) asserts that

cultural care knowledge derived from the people, the emic culture knowledge, could provide the truest knowledge base for culturally congruent care so that people would benefit from and be satisfied with nursing care practices held to be healthy ways of serving them. (p. 36)

Nurses are recognizing that an important part of our role is to negotiate with clients to arrive at health care goals and interventions that meet client needs while respecting cultural values and beliefs. If the client does not accept the interventions as valid, the plan will not be successful. To gain the knowledge necessary to become culturally competent, nurses must be able to participate with and learn from the communities they serve (DeSantis, 1997; Leininger, 1997b; Leininger & McFarland, 2002; Spector, 2004). It was anticipated that the knowledge of professional and generic caring practices generated from this study will allow nurses to identify the scope of changes that are necessary to provide culturally congruent care to South Sudanese LBLG refugees. It was predicted that new modes of caring would be discovered, which when put to use, will result in the increased trust and satisfaction of those receiving care.

The United Nations High Commission for Refugees (UNHCR) and the U.S. Committee for Refugees and Immigrants (USCRI) estimate that as of December 2008 there were more than 14 million refugees and asylum seekers worldwide (USCRI, 2008). While developed countries provide the majority of funding to provide assistance to

refugees, nations with per capita income of less than \$2,000 host more than two thirds of all refugees. In 2008, the United States ranked sixth in refugee resettlement among developed nations, resettling 48,281 refugees, the majority of whom arrived from the least developed countries of the world. Refugees arrive with significant health care risks, many having experienced trauma or torture and the loss of family, jobs, homeland, social status, health, culture and identity (Burgess, 2004; Carolan, 2009; Davis, 2000; Keyes, 2000; Muecke, 1992b; Palinkas et al., 2003; Robertson et al., 2006; Weaver & Burns, 2001). Many believe that upon reaching the safety of our shores, their problems will cease. Instead, they are faced with post-migration stressors of adjusting to a new country, language, means of employment, education and health care systems, along with potential challenges brought by intolerance, stigmatization and rejection (Burgess, 2004; DeSantis, 1997; Keyes, 2000; Lipson, 1992; Lipson & Omidian, 1997; 2006; Smith, 2001). The reality is that there are many challenges to face, and refugees often have limited resources to handle them. The International Council of Nurses (ICN, 2006) asserts that the poor health of refugees may be compounded by a lack of resources in the country of resettlement. The ICN challenges nurses worldwide to contribute to the resolution of the health problems experienced by migrants, refugees and displaced persons through advocacy and care which address their needs and assist them to adjust to a new way of life. Lack of resources, as well as cultural and linguistic barriers present in interactions between refugees and health care providers, have compromised quality of care, leaving both refugees and health care providers dissatisfied (Davis, 2000; Muecke, 1992b; Palinkas et al., 2003; Robertson et al., 2006; Smith, 2001).

Refugee populations in resettlement, including those from Africa, are understudied given their health risks (Barnes, Harrison, & Heneghan, 2004; Carolan, 2009; Kanya, 1997; Renzaho, 2004; Robertson et al., 2006; Willis & Nkwocha, 2006). While the numbers of refugees resettled in the United States from African countries remain small compared to those who come from Latin America and Asia (USCRI, 2006), numbers of African refugees are growing. The United States admitted 60,680 refugees and asylees in 2007, about one-third of whom were from Africa (Terrazas, 2009). Women are likewise underrepresented in refugee health research, with the notable exception of studies which focus on their roles in child-bearing and child-rearing. Such a limited focus defines women solely by their reproductive role, ignoring the impact of gender on other variables which affect health and/or well-being. At the same time they are often excluded from education and training opportunities in the camps, which may be available only to men (International Council of Nurses, 2006; Muecke, 1992a). All of these factors are likely to have an impact on the health and well-being of female refugees following resettlement (Berman, Giron, & Marroquin, 2006; Robertson et al., 2006). Nursing research inclusive of all voices within African refugee communities is essential to increase knowledge and understanding of culturally influenced health care beliefs and practices so that nurses can minimize the special health risks of resettled refugees.

In October, 1991 the American Nurses' Association (ANA) Council on Diversity in Nursing Practice published a position paper titled *Cultural Diversity in Nursing Practice* in which it states that the concepts of illness and wellness are derived from a cultural perspective or world view. The ANA position paper identifies culture as one of the organizing concepts upon which nursing is based and defined. It maintains that nurses

must have knowledge of how cultural groups define health and illness, maintain wellness, identify the causes of illness, as well as how traditional healers cure and provide care.

The *Nursing Social Policy Statement* builds on this position paper with its mandate that nurses apply culture care knowledge through the provision of culturally congruent care (American Nurses Association, 2003). Knowledge generated through this study of health care beliefs and caring practices of South Sudanese LBLG refugees will prepare nurses to meet the standards for the provision of culturally congruent care mandated by our professional organization.

Michigan became the new home for one of the largest numbers of LBLG of Sudan. While completing a nursing practicum, the researcher had the opportunity to meet many of these young people at the local county health department soon after their arrival in the United States. The majority arrived appearing overwhelmed, with many questions about their health and what they should do to become healthier. Many of these young refugees, all of whom were men, showed evidence of malnutrition, visual and hearing disturbances, dental problems, and parasites. Symptoms commonly experienced included headaches, joint pain, abdominal discomfort, and sleep disturbances. Challenges abounded for both the nurses and young men as they communicated within the context of their different experiences and worldviews.

As a result of this experience, the researcher saw the need for, and completed, a mini-study in preparation for this study designed to elicit knowledge of the health care beliefs and practices related to health and well-being of South Sudanese lost boy refugees. While significant preliminary knowledge resulted from this mini-study, limitations included (a) a lack of data saturation, (b) inclusion criteria that limited

participants to men who identified themselves as Dinka, and (c) the need to limit participants to those living in a specific mid-sized city. While the numbers of lost girls in the United States are small, it became evident during data collection that their knowledge has a strong impact on the community as a whole, and the few who are present must be represented in any studies relating to health and well-being. The researcher also came to realize that although the majority of LBLG identify themselves as Dinka, other Nilotic tribes are represented in the community. Finally, in seeking follow-up interviews with key informants, it became evident that many members of the LBLG community in the United States had not “settled” in the specific communities where they were initially placed by the USCRI in coordination with local refugee organizations. Instead, the LBLG communities remained nomadic, many moving at short notice across the country to join friends and/or kin or in search of better job or educational opportunities. Members of the community remained connected through frequent phone calls and cross country trips. Several participants spoke of driving 1000 or more miles for a weekend visit. The community is larger than a geographic area, and has instead become a shifting diaspora of young people throughout the United States

The literature related to health and well-being of South Sudanese refugees, though scant, indicates the existence of significant health problems, particularly in relation to mental health (Bolea et al., 2003; Geltman, Grant-Knight, Mehta, Lloyd-Travaglini, & al, 2005; Jeppsson & Hjern, 2005; Lustig, Weine, Saxe, & Beardslee, 2004; Power & Shandy, 1998). Currently there is very little known about the health care beliefs and practices of South Sudanese refugees, including the LBLG. A study of culture care meanings, beliefs and practices of the LBLG of Sudan will be a first step in filling the

gap in the research and developing a knowledge base for the development of culturally congruent caring practices.

## 1.7 Orientational Definitions

The 1951 United Nations Geneva Convention Relating to the Status of Refugees and its 1967 Protocol established the legal standards for refugee protection and provided the legal definition of refugee endorsed by 134 nations including the United States.

According to the Convention, a refugee is

Any person who, owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable, or owing to such fear, is unwilling to avail himself or the protection of that country (UNHCR, 1951, 1967).

Media coverage of current conflicts, including those in Iraq, Afghanistan, Pakistan, and Darfur, has raised the consciousness of many about the plight of refugees, asylum seekers and displaced persons. Asylum seekers and internally displaced persons are similar to refugees in their experiences of war, persecution, loss of family and permanent loss of country (Hollifield et al., 2002; Howard & Hodes, 2000; Weaver & Burns, 2001). An internally displaced person has been forced from home for the same reasons as a refugee, but remains within the borders of his/her own country. Because the person is still under the jurisdiction of a government that might not want international agencies to help him or her, an internally displaced person remains vulnerable to persecution or violence. In contrast, an asylum seeker has made his or her way to a country where asylum is sought. International law recognizes the right to seek asylum, but does not oblige states to provide it. If the receiving country determines that the person



does not qualify for asylum, the person may be sent back to the country from which they fled (USCRI, 2005).

There are concerns with the use of legal definitions in refugee research. These definitions are influenced by world politics and the policies that result from them. For example, past policies of the U.S. Immigration and Naturalization Service prevented the classification of Central Americans, Haitians, and Palestinians as refugees (Lipson, 1993). At different times during the years of their flight, the LBLG have met the criteria for asylum seekers, internally displaced persons, and refugees. Their friends and family members, who were internally displaced or seeking asylum within the borders of neighboring African nations, may have lacked the opportunity to seek official refugee status, or have been denied such status. From a humanitarian perspective, all of these people were deserving of a safe place to live and raise a family. Yet, of those whose petition for refugee status was successful, only a small percentage was chosen for resettlement in a third country. For every LBLG who formally met the criteria for resettlement as determined by the UNHCR, there were scores more in the same situation who were never granted that opportunity.

The following definitions have been defined for the purposes of this ethnonursing study:

*Care*. “The abstract and manifest phenomena and expressions related to assisting, supporting, enabling, and facilitating ways to help others with evident or anticipated needs in order to improve health, a human condition, or a lifeway” (Leininger, 1996, p. 73).

*Culture.* Refers to the learned and shared beliefs, values, and lifeways of South Sudanese LBLG refugees that are transmitted intergenerationally and influence thinking and action (Leininger & McFarland, 2002).

*Culture care.* According to Leininger (1996),

. . . refers to culturally derived, assistive, supportive, or facilitative acts toward or for another individual or group with evident or anticipated needs which guide nursing decisions and actions and are held to be beneficial to the health or the well-being of people, or to face disabilities, death, or other human conditions. (p. 73)

*Generic care.* Refers to the lay, folk, indigenous, and known care values, beliefs, and practices used by South Sudanese LBLG refugees over time (Leininger, 1996).

*Professional care.* According to Leininger (1996), “refers to values, beliefs, and practices of a body of knowledge that has been learned in professional schools and held by health professionals to be therapeutic or beneficial to clients” (p. 73).

*Culturally congruent care.* According to Leininger and McFarland (2002), “refers to the use of sensitive, creative, and meaningful care practices to fit with the general values, beliefs, and lifeways of clients for beneficial and satisfying health care, or to help them with difficult life situations, disabilities, or death” (p. 12).

*Worldview.* Refers to the way South Sudanese LBLG refugees look out upon and understand the world around them, and provides a value stance, picture, or perspective about their life and world (Leininger, 1997a).

*Ethnohistory.* According to Leininger and McFarland (2002), “refers to the sequence of facts, events, or developments over time as known, witnessed, or documented about a designated people of a culture” (p. 83).

*Cultural and social structure dimensions.* According to Leininger (1997), “refers to the dynamic, holistic, and interrelated patterns or features of culture (or subculture)

related to religion or spirituality, kinship (social), political (and legal), economic, education, technology, cultural values, language, and ethnohistorical factors of different cultures” (p. 38).

*Emic.* Refers to South Sudanese LBLG refugees’ views and values about a phenomenon (Leininger, 1997).

*Etic.* According to Leininger (1997), “refers to the outsider’s views and values about a phenomenon” (p. 38).

*Environmental context.* Refers to “the totality of an event, situation, or related life experience that gives meaning and order to guide human expressions and decisions within a particular environmental setting, situation, or geographic area” (Leininger, 1997, p. 38).

*Health.* According to Leininger (1991), “refers to a state of well-being that is culturally defined, valued, and practiced, and which reflects the ability of individuals to perform their daily role activities in culturally expressed, beneficial, and patterned lifeways” (p. 48).

*Refugee.* According to UNHCR (1971), refers to

any person who, owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable, or owing to such fear, is unwilling to avail himself of the protection of that country.

*Dinka.* Refers to those people who identify themselves as Dinka.

*Nuer.* Refers to those people who identify themselves as Nuer.

## 1.8 Assumptions

The following theoretical assumptive premises which relate to the domain of inquiry and will be used to guide this study are derived from select assumptive premises of the theory of culture care.

1. Care is the essence of nursing and a distinct, dominant, central, and unifying focus (Leininger, 1991).
2. Culture care values, beliefs, and practices of South Sudanese LBLGs are influenced by and tend to be embedded in the worldview, language, religious (or spiritual), kinship (social), political (or legal), educational, economic, technological, ethnohistorical, and environmental context (Leininger, 1996).
3. Culture care for South Sudanese LBLGs is essential for their health, well being, growth, survival, and to face hardships or death (Leininger, 1997a).
4. Culture care concepts, meanings, expressions, patterns, processes, and structural forms of care vary transculturally with diversities (differences) and some universalities (or commonalities) to be expected between western health care providers and South Sudanese LBLGs as well as among the LBLGs themselves (Leininger, 1997a).
5. Every human culture, including that of the South Sudanese LBLGs, has generic (lay, folk, or indigenous) care knowledge and practices which vary transculturally (Leininger, 1996).
6. Culturally congruent or beneficial nursing care for South Sudanese LBLGs can only occur when the refugees' individual, group, family, community, or institutional care values, expressions, or patterns are known and used explicitly by the nurses in appropriate and meaningful ways (Leininger, 1997a).

## 1.9 Summary

The growth in the number of refugees in the United States presents enormous challenges for nurses and other health care providers. Refugees are a vulnerable population. As a group, they are at high risk for health problems, particularly in relation to mental health, as a result of both their pre-migratory and post-migratory experiences. They face many challenges yet often have limited resources to handle them. Nurses must be able to recognize the many challenges and barriers that exist, and work within the context of the refugees' culture to identify ways to provide meaningful and safe care.

Many barriers exist for the young refugees from South Sudan who have arrived from one of the least developed countries in the world without parents and few family members here to guide them. A study focused on teasing out the emic perspective of the LBLG in regard to health and well-being will offer knowledge to nurses which will allow for the development of culturally congruent caring practices. Ultimately, this will benefit both health care providers and the South Sudanese youth through increased understanding, trust, and satisfaction with culturally sensitive care that leads to improved health and well-being.

# Chapter 2

## Review of the Literature

### 2.1 Sudan

Sudan is the largest country in Africa. It covers an area of 967,490 square miles, which is more than one quarter the size of the United States (Bateman, 2002). Sudan is surrounded to the north by Egypt, to the northeast by the Red Sea, to the east by Ethiopia and Eritrea, to the south by Kenya, Uganda, and the Democratic Republic of the Congo (D.R.C.), to the west by the Central African Republic and Chad, and to the northwest by Libya (Dicky, 2001). Khartoum, the capital of Sudan, is located in the northeast part of the country and serves as the political center of North Sudan. The capital of South Sudan is Juba, where the newly formed government of the semiautonomous south is building a state from scratch (see Figure 1).

The land rises all along the southern borders of Sudan, reaching its highest point at Mount Kinyeti on the Ugandan border. From there it slopes gently down, reaching a vast clay plain which covers much of southern and central Sudan. The impermeability of the clay soil gives rise to flooding during the rainy season, while during the dry season the mud becomes cracked and dry. The Bahr el Jebel (White Nile) and Bahr el Ghazal (Nam) rivers flow through the plain, eventually merging into a vast swamp, the *Sudd* (Bateman, 2002). Historically, the *Sudd* provided a physical barrier which served to

Hjern, 2005).

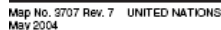


Figure 1

Map of Sudan (United Nations, 2004)

The highlands areas, which are only slightly elevated from the surrounding flood plains, provide drier ground during the wet season where permanent villages can be built. Vegetation in the highlands includes open woodland areas with tall grasses. The heat of the dry season burns the grasses, making cattle grazing impossible. The *toic*, at slightly lower elevations than the highlands, is land which is seasonally saturated by the overflowing rivers, retaining enough moisture throughout the dry season for cattle grazing. The *Sudd*, the area of lowest elevation, is a permanent swampland which provides good fishing, but is not available to livestock (Human Rights Watch, 2003).

There is a dramatic difference between the wet and dry seasons in South Sudan. In the dry season areas of permanent habitation are hot and parched, so the cattle must be moved closer to water sources including rivers and the seasonally flooded *toic*. In the wet season, as the lower plains flood, the people return with the cattle to the higher, dryer grounds. Seasonal migration and a pastoral economy become a necessity for survival in such a land and climate. Cultivation of crops is possible, although the output is generally below subsistence level due to limited land size and the irregularity of the rains (Deng, 1972). Areas which have been able to support the largest populations have been those with large areas of highlands that provide habitable land with access to flood-fed seasonal grazing (Human Rights Watch, 2003). A planned dam and canal system, the Jonglei project, is proposed to increase and control the flow of the Egyptian Nile, and provide adequate water for crop irrigation in Sudan. If the project is completed as planned, it will threaten to eliminate the pastoral culture of the Dinka and Nuer, which has been a point of contention in the north/south conflict (Jeppsson & Hjern, 2005).



Oil was discovered in Sudan in 1978. The vast areas of oil production are predominately found in parts of the flood plain in the regions of Bahr El Ghazal and the Upper Nile in South Sudan, much of which is in traditional homelands of the Dinka and Nuer (see Figure 2). Control of these lands has been contentious, with southern rebel forces controlling the areas from 1984 to 1999, after which much of the area was captured by government forces. The pastoral Dinka and Nuer living in these areas were forcefully displaced by government forces starting in 1999 so that international oil companies who “owned” the oil rights could be brought in to begin production. Further displacement occurred in areas throughout the Muglad Basin as oilfields expanded and production increased (Human Rights Watch, 2003).

## 2.2 Historical Overview

The tensions between north and south Sudan have been shaped by historical and contemporary inequalities between the two regions, resulting from prejudices based on race, ethnicity, religion, culture, politics, gender, and identity (Deng, 1995; Holtzman, 2000; Jok, 2001). Over the course of the eleven centuries following the rise of Islam, many Arab groups arrived in what is now Sudan as traders. Some remained in the area, intermarrying with the indigenous population, creating the foundation of the present Sudanese society in the north (Duany, 2003). The early 19th century began a period of foreign domination and exploitation of the south, starting with the Turco-Egyptian rule which lasted from 1821 to 1881. During this time areas in the south were subjected to frequent, intense slave raiding from the north. As a result of the slave raids, the peoples

of South Sudan, including the Dinka and Nuer, avoided contact with the northern Arab population and rejected Arab ways (Deng, 1995; Jok, 2001).

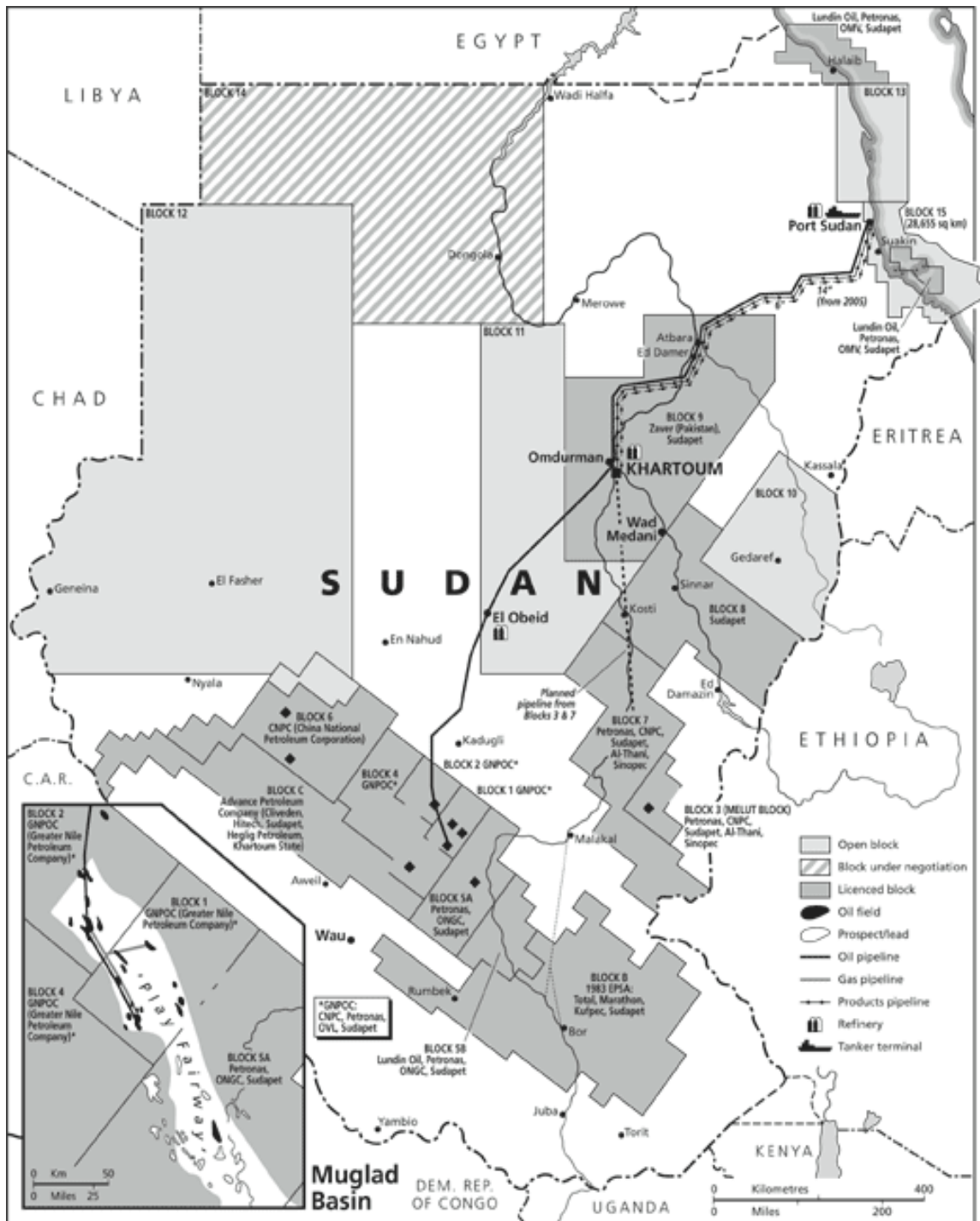


Figure 2

Oil Concessions in Sudan

In 1881 a northern Sudanese leader proclaimed that he was the Mahdi, divinely appointed to chase the Turco-Egyptian regime out of Sudan. Great Britain and Egypt successfully joined forces, and ultimately halted the rebellion. The British and Egyptians were unlikely partners, yet were united in their desire to control the waters of the Nile. The Anglo-Egyptian Condominium ruled according to British colonial policy which resulted in the abolishment of slavery and the development of separate administrative regions in the north and south of Sudan. The separation of regions allowed for the reinforcement of Arabism and Islam in the north, and resulted in development in the south along indigenous African lines. Economic, social, cultural, and educational developments were confined to the north, where Khartoum was established as the administrative and legislative capital of the country. Colonization also brought about some exposure to Christian education and Western values in the south through British missionaries and priests. The south was exploited through policies which allowed for the plundering of natural resources for development in the north. Isolation resulted from the separation of north and south, halting any cross-cultural influence that had previously existed. While the north grew in wealth, the peoples of the south continued to live much as they had for centuries before. Disparities have continued to grow since independence, with the north now the center for industrial development, government, health care, and education (Deng, 1995; Duany, 2003; Holtzman, 2000; Jok, 2001).

War between the north and south of Sudan broke out in August, 1955, just 4 months before Sudan declared independence from Britain on January 1, 1956. Subsequent governments and military regimes in the north attempted to unite the country through policies focused on forced assimilation of the south. Islamic law was mandated

throughout the country, and Arabic was made the official language in all schools. The most recent phase of the war, which began in 1983, pitted the main southern rebel army, the Sudan People's Liberation Army (SPLA), and its allies against the northern government's military and its allies. The majority of the fighting has occurred in the impoverished southern regions of the country. According to the USCRI (2000), the government and its allies regularly attacked civilian targets throughout the south, including hospitals and camps for displaced persons. Rebel troops also committed atrocities against their own civilians as ethnic tensions and fighting erupted between Dinka and Nuer rebels. Apart from an 11 year hiatus from 1972 until 1983, the war continued unabated until the signing of a comprehensive peace agreement in January, 2005. The war left millions dead, and up to 5 million Sudanese were internally displaced, the largest internally displaced population in the world. An estimated 465,000 Sudanese were living outside Sudan as refugees and asylum seekers at the end of 2001. Among these were the 3,800 lost boys and lost girls of Sudan who were eventually resettled in the United States between November 2000 and September 2001 (USCRI, 2001).

## 2.3 Ethnohistory

As with all other peoples, the beliefs, values and worldview of the LBLG have been shaped by the generations who came before them. A wealth of ethnographic knowledge has been documented about the peoples of the Nilotic regions of South Sudan, including the Dinka and Nuer, yet understandably ethnographic literature focused specifically on the LBLG is scant. While they share the culture of their parents and kin, the LBLG grew up living among people of different cultures in institutional settings,

where many of the norms of camp governing organizations were reinforced by rules and regulations. The Lost Boys early years in Ethiopian refugee camps afforded them a vastly different way of life than that which they would have experienced growing up in a traditional community setting, with boys and girls, children and adults, sharing life together. Schechter (2004) speaks to the influence of institutional camp life in shaping the values and beliefs of the Lost Boys:

Their early incubation as the youngest cadre within SPLA camps in Ethiopia enforced a break from normative engagement within cyclical family and communal relations and actions. Since transferred to UNHCR institutional care, they have been accorded the “right” and prerogative by agencies to redraw gender, generational, and ethnic relations. (p. 312)

Given these circumstances, and the influence of their cosmopolitan experience, it is anticipated that the worldview, values and norms of the LBLG will vary somewhat from that of their kin who did not share their collective experience in the camps and in exile. This ethnohistory of the LBLG will briefly examine traditional cultural factors, with an emphasis on those which are most likely to influence the lives of the LBLG today. There is an emphasis on traditional values, as without understanding the cultural roots of the LBLG it will be very difficult to recognize and understand transformations and consistencies in relationship to the traditional beliefs and values that bring meaning to their lives today. Leininger’s Sunrise Model will be used as a guide to explore the ethnohistory, cultural and social structure dimensions of the LBLG within their shifting environmental contexts. The cultural and social structure dimensions include cultural values, beliefs and lifeways, political and legal factors, economic factors, education, technological factors, religious and philosophical factors, and kinship and social factors.

Much of the ethnography with the Dinka and Nuer results from field work conducted between 1930 and 1960 by such eminent anthropologists as Evans-Pritchard

and Leinhardt (Evans-Pritchard, 1940; Lienhardt, 1961). Evans-Pritchard's ethnographic work among the Nuer is most famously documented. His books, including *The Nuer: A Description of the Modes of Livelihood of a Nilotic people*, *Kinship and Marriage among the Nuer*, and *Nuer Religion*, are required reading in anthropology curricula around the world. This fame has resulted in a common perception of the Nuer and other Nilotic peoples as locked in time, as if they all still live a pastoral lifestyle in the relative isolation of South Sudan as they did in the first half of the 20th century. The reality couldn't be more different. This historically frozen perception of the Nuer and Dinka fails to take into consideration the catastrophic changes wrought on life and livelihood by the past 50 years of intermittent civil war, as Hutchinson (1996) demonstrates so clearly in her book, *Nuer Dilemmas: Coping with Money, War and the State*. The war has shaped the lives of the LBLG, most of whom fled their villages at a very young age, independently of their parents, eventually finding their way to refugee camps where they lived among their peers in challenging circumstances for many years.

## 2.4 The People and Languages

The group identity of the LBLG of Sudan was forged by virtue of their being granted refugee status following exile from Sudan as unaccompanied minors. Data were not collected relating to ethnic identity when they were admitted to the United States; however, records from Kakuma Refugee Camp in Kenya indicate that the youth selected for resettlement almost all identified themselves as Dinka (95%) and Nuer (5%) (Fitzgerald, 2000). A small minority of the LBLG living in the United States identify themselves as belonging to ethnic groups originating in Equatoria (Bowles, 2005).

The Dinka are a group of closely related peoples. They are the largest ethnic group in South Sudan and are made up of a number of subgroups, including Dinka Malual, Tuic, Rek, Ruweng, Bor, Agar, Atwot and Ngok. The Dinka people share a common language with differing, but mutually understandable, dialects. The Nuer are the second largest group of Nilotic peoples in South Sudan. They are related to the Dinka, often live in close proximity to them, and speak a language that is closely related to that of the Dinka. The principal subgroups of the Nuer are Jikany, Gawaar and Lou, and like the Dinka, a wide variety of accents are evident (Jok, Leitch, & Vandewint, 2004). Virtually all of the LBLG were multilingual upon arrival in the United States. Many speak their mother tongue in addition to Dinka, Nuer, Arabic, Kiswahili and English. The majority of LBLG arrived with a good grasp of spoken English, which they studied in school at Kakuma. The languages most frequently spoken between LBLG who do not understand one another's native tongues are English and/or Arabic (Bowles, 2005).

## 2.5 Worldview

Early ethnographic representations of the Dinka and Nuer speak to a worldview based on cattle, which were not only valued as a food source, but were also central to understanding patterns of kinship, social interaction, religion, political structure, and economics (Deng, 1972; Evans-Pritchard, 1940; Lienhardt, 1961; Seligman & Seligman, 1932). The extensive, forced social change which has resulted from years of colonial rule, war, displacement, and increased interaction with other peoples of the world, has clearly brought about a change in worldview. In discussing a conversation with a Dinka elder from Bahr al-Ghazal, Schechter (2004) speaks of the elder telling him with a wry laugh,

“The lesson about the cow, we can forget that one” (p. 87). This reference reflects a transformation in worldview resulting from rapid social change. This theme of transformation is apparent in contemporary studies with Dinka and Nuer both within Sudan (Hutchinson, 1992; Hutchinson, 1996; Jok, 1999, 2001; Jok & Hutchinson, 1999) and in the diaspora (Abusharaf, 2002; Bagenda & Hovil, 2003; Holtzman, 2000; Schechter, 2004; Shandy, 2001, 2002).

## 2.6 Religion

The state religion in Sudan is Islam, whose adherents, primarily Sunni Muslims, make up somewhat more than half of the population. The majority of Muslims, about 90%, live in the north of the country, where they make up 75% of the population. The minority Christian population is estimated at between 4% and 10%, while approximately 33% of Sudanese adhere to indigenous religions. At the onset of the Anglo-Egyptian Condominium, the south of Sudan was sectioned into three “spheres of religious influence,” which were divided among the various denominations with missions, including Catholics, the Anglican Christian Missionary Society (U.K.), and the American Presbyterians. The separate spheres were developed to allow for evangelical activities by the various Christian missions without the potential for competition and sectarian rivalries. The British hoped that the missionaries would proselytize, thereby limiting the spread of Islam. Mission stations, set up in all three spheres, focused on evangelistic activities, Bible translation, education, and health care (Pitya, 1998). Numbers of converts increased, eventually reaching an estimated one to two million South Sudanese Christians today. The majority of Christians are Roman Catholic, although Anglican,



Presbyterian, Greek Orthodox, and Lutheran religions are also well represented (Dicky, 2001).

In September 1983 the former Sudanese head of state, Jaffer Nimeiri, imposed a code of Islamic laws, known as *sharia*, throughout the land. Most constitutionally guaranteed rights were suspended. Traditional Islamic punishments were imposed for theft, adultery, homicide, and other crimes. The zealousness with which these punishments were carried out contributed to the fall of Nimeiri. Nevertheless, no successive government has repealed the harshest laws of *sharia*. The imposition of *sharia* was not popular among Sudanese, including many Muslim groups in the north; however it was of particular concern to those in the south who saw *sharia* as a threat to their culture and way of life.

The Dinka and Nuer peoples are very religious. Indigenous Dinka religion is not focused on what happens to one's soul in the world to come; rather, "it is rooted in Dinka demands for a secure life in this world and continued participation after death" (Deng, 1972). While there is a belief in one God, many people believe that supernatural spirits, or divinities, play an important and more direct role in the lives of people. The actions of spirits are known to have an impact on health and well-being. Deng notes that

A spirit may also be called upon to mediate between man and another good or evil spirit. Spirits usually have particular characteristics that manifest themselves through human experience. Some of them are known to inflict specific types of pain or illness. Some are known to have certain likes and dislikes. When they "fall upon" a man and possess him, they can be identified by the aberrational behavior they induce in him. (p. 123)

It is not unusual for people to integrate elements of Christianity with elements of indigenous beliefs. Many Nuer and Dinka men and women believe that their sufferings are the result of a curse from God. A large number who have sought spiritual refuge from

the war through conversion to Christianity, believe that God is punishing them for their earlier “slowness in abandoning the worship of false gods” (Hutchinson, 2001). As a result of these beliefs, many feel that their best means of survival is to place their faith in the Christian message and in the compassionate forgiveness of God. A disproportionate number of the Christian population at Kakuma have been resettled in the United States, possibly because their claims to asylum were considered to be most well-founded as a result of the persecution due to religion clause in the UNHCR definition of refugee (UNHCR, 1967).

## 2.7 Education

During the Anglo-Egyptian Condominium the British left education in the south to the missionaries. This led to an entwinement of religion and education. Those who attended school became Christians, joining the denomination of the missionaries running their school (Deng, 1972). Discussion and debate, which continue today, could arise within families as sons returned home as Christian converts. Tensions were not too great as there are inherent similarities between Christian worship and Dinka traditional religions. In addition, worldview, symbols, and the language used to describe God are nearly identical (J. M. Jok, personal communication, November 29, 2006). Schools worked at forming good relationships and changing the attitudes of the people towards education. The students themselves became ambassadors for education as they shared their knowledge of reading and writing at home. Francis Deng (1972) suggests that “for the Dinka, who see a linkage between knowledge and mysticism, writing and reading

came to assume a respected place in their system of values as sources of wisdom” (p. 154).

While education became available for the small number of boys whose families allowed it, education remained unacceptable for girls. It wasn’t considered safe for girls to be away from home. People also worried that boys in the family would not be able to marry, as they would be deprived of their sisters’ bridewealth if their sisters became educated and delayed marriage. Bridewealth is the payment, in cattle or cash equivalency, presented by the family of the groom to the family of the bride as part of the marriage agreement. The bridewealth received when daughters marry is often used to provide the bridewealth necessary for sons to marry (Duany, 2003).

Education for some, but not all, contributed to the development of social classes. In her memoir, Julia Duany (2003), a Nuer woman now living in the United States, speaks of changes that occurred, some more positive than others, after she moved from her home village to a Catholic boarding school. “The more we learned, further [*sic*] we moved away from our community. We becoming *turuk* (modern and civilized) people and learning that our own culture was undesirable, primitive, and backward” (Duany, 2003, p. 88).

The language of education in the missionary schools was English. Following independence, the government in the north took over all schools. The relationship between the government and Christian missionaries deteriorated, culminating in the expulsion of all foreign missionaries from Sudan in 1964. Arabic replaced English as the language of instruction. The focus of education shifted from a Westernized Christian perspective to a Muslim-Arab perspective. There was no formal educational offering

from a traditional Dinka or Nuer perspective. As the conflict between north and south grew, many schools were destroyed, and few children were able to attend those that stayed open. The government of Sudan has made a commitment to education for all by 2015, but there currently is little evidence that a plan has been developed to achieve this. Literacy rates are low, with 71.8% of men and 50.5% of women over the age of 15 reported able to read in 2004 (UNESCO Institute for Statistics, 2004). With most of the fighting occurring on southern soil, it is likely that literacy rates for those in the south were much lower.

## 2.8 Political and Legal Systems

Sudan has experienced political instability since independence was proclaimed in 1956. The current president, Omar Hassan al-Bashir and his National Congress Party (NCP) have controlled the government since his rise to power in a military coup in 1989. Currently there are 26 states in Sudan, whose cabinets and officials are appointed. Funding for each state is determined by the central government in Khartoum (Dicky, 2001).

Sudan is currently in a transitional period following the signing of the Comprehensive Peace Agreement (CPA) in January 2005, which marked the formal end of the civil war between the government and the SPLA/M. The Interim National Constitution and the Constitution of Southern Sudan were ratified in 2005. SPLA leader John Garang became Vice-President of the new post-war government of national unity, while al-Bashir continued as President. Sixteen members of the government and nine members of the SPLA were appointed ministers in the new government. The NCP

maintained control of the key ministries, including the Ministry of Energy and Mining, which controls the vital oil industry (Wikipedia Encyclopedia, 2006).

The National Legislature, which is the new parliament, has two chambers. The National Assembly consists of 450 appointed members who represent the government, former rebels, and other opposition political parties. The Council of States has 50 members who are indirectly elected by state legislatures. Legislators are appointed to six-year terms. Islamic law remains in the north. The legal system in the south is still developing under the CPA. *Sharia* no longer applies to the southern states (Central Intelligence Agency, 2006). The terms of the CPA allow for autonomous rule in South Sudan for 6 years. During this period oil revenues will be evenly divided between north and south. At the conclusion of the six year period, the peoples of South Sudan will vote in a referendum on independence (United Nations Office for the Coordination of Humanitarian Affairs, 2006a).

## 2.9 Economics

Before the wars, cattle were the mainstay of the culture and the basis of the economy. According to the UNCRI (2000),

Cows are the centerpiece of diet, commerce, and religion. Families rely on cows for nutritious milk and meat, for bartering to gain money and goods, for dowries to arrange marriages and for sacrificial killing to honor gods and ancestors. Cows are a source of dignity and self-esteem for most Dinka men.

Boys and young men have been responsible for the cattle and drive them to new pastures in search of grazing during the dry season. In more recent years, money has been introduced, bringing with it changes in the traditional system of marriage and family ties based on the exchange of bridewealth (Hutchinson, 1996).

The economy of Sudan has been adversely affected by years of civil war, political instability, drought and famine. Foreign debt exceeded \$17 billion as of 2005, one of the world's largest foreign debts (United Nations Office for the Coordination of Humanitarian Affairs, 2006b). There are large disparities between rich and poor, with most of the population struggling to survive. Years of decreased rainfall have taken a toll on crops. The transportation infrastructure is poor, making it difficult to transport materials and goods over distances. Yet, economically, South Sudan has the potential to become one of the wealthiest regions in Africa. Its wealth includes cattle, oil, gold, diamonds, uranium and rich soils (Beswick, 1998). Such wealth must be far from the minds of those people now returning from displaced persons' camps to find their homes and villages destroyed, schools vacant, and no health care facilities in sight. Post-war challenges will require reconstructing communities whose values, institutions, structures, and cultural patterns have been shattered. This will require the population to respond to the radical changes they have undergone and to build on those elements of the culture which have brought them so much strength in the past (Deng, 2003).

## 2.10 Kinship Structure

A key finding from a study funded by Save the Children and focused on the vulnerability of people living in South Sudan, was that Dinka participants defined vulnerable people as “those without an adequate kinship structure around them to protect them” (Harrigan & Chol, 1999, p. iv). Kinship ties are extremely important to the Dinka and Nuer, with family members providing an essential support network. Julia Duany (2003) describes kinship among the Nuer as “a communal bond that binds past, present

and future generations together” (p. 77). One important family unit consists of those who belong to the same subclan. Leinhardt (1961) defined subclans of the Dinka as “all of those who come into contact with each other who know themselves to be agnatic descendants of an original ancestor” (1961, p.8). This patrilineal structure theoretically allows everyone to trace their ancestors back to a single person. The closer the connection of the descent group, the more that is expected from one another in the way of alliances and mutual support.

Another vitally important family unit consists of those people in the extended family who contribute to the bridewealth. This grouping, which includes family in the patrilineal line as well as relatives connected by marriage, is expected to provide unquestioning support for one another. Traditionally marriages are arranged between the men of the families involved. Marriages bring together two sets of extended families, in a relationship that is contracted and sustained through payment of bridewealth from the extended family of the man to the extended family of the woman. Historically, the system of marriage has kept families strong in time of crisis, and provided safety and security for women and children. Since bridewealth is given from one extended family to another, it serves to strengthen the bonds between the families. If a woman or her children are mistreated by either her husband or his family, members of her extended family may intervene with the husband’s family on her behalf. Often just the knowledge that his wife’s family is aware of a problem is enough to change the husband’s behavior. Divorce is very rare, and strongly discouraged. It is economically challenging, since bridewealth, which has been distributed throughout an extended family, will need to be returned. As a

result, the extended family has a stake in the marriage and will bring pressure to bear on the couple to find a way to resolve their differences (Deng, 1972; Duany, 2003).

## 2.11 Cultural Values and Lifeways

Unity and harmony, which are experienced when a sense of balance and order is present, are highly valued in both the Dinka and Nuer cultures. These concepts are expressed by the Dinka with the verb *cieng*, which literally means “to live together” and “to look after.” There is a caring element implied in *cieng*, which Deng (1972) describes as a concept of ideal human relationships. *Cieng* is learned at home among family, yet it is idealized in the much broader sense of people living together in the village, community, or country. *Cieng* has the status of a moral code inherited from the ancestors. A concept closely related to *cieng* is *dheeng*, which reflects the honor, dignity and pride of an individual. Deng explains that “the social background of a man, his physical appearance, the way he walks, talks, eats, or dresses, and the way he behaves towards his fellow men are all factors in determining his *dheeng*” (p. 14). *Cieng* and *dheeng* are closely related; a person would not be capable of acquiring the virtue of *dheeng* if *cieng* did not define the moral standards required to achieve it. The Nuer concept of *mal* evokes similar meanings as the Dinka *cieng*. Duany (2003) describes *mal* as an ideal of peace, unity, health, unbroken wholeness; it is experienced as a state of dynamic equilibrium. The importance of this value to the Nuer is reflected in a common greeting within families, “*mal puony du*, is your body at peace?” (Duany, 2003, p.53).

Continuity of the lineage through procreation is of vital importance to the Dinka and Nuer, and is the most important function of marriage. A woman strengthens her



position in a family by producing children. While all children are loved and valued, sons are necessary for continuity of the lineage. A man who dies without sons, who has no one to carry on his name and to remember him, is considered truly dead. Sons link the lineage from the past, through the present, to the future generations, and as a result bring immortality to their fathers and the lineage. Dinka and Nuer naming systems reflect the importance of the lineage. A son is given his own name at birth, followed by the name of his father, the name of his grandfather, the name of his great-grandfather, and so on. At a very young age children are taught to memorize and recite their father's genealogy to the most distant known ancestor. Important connections with ancestors are honored as the paternal lineage is recited back through twenty generations or so, by name (Deng, 1972; Duany, 2003).

The Dinka and Nuer have a system which allows a family to maintain continuity of the lineage from generation to generation even when a man has no sons to follow him. If a man is married, and dies without sons, or is absent for years because of war, responsibility for ensuring that his name continues falls to his family. The family will choose a kinsman, usually a brother, to have children for him with his widow or abandoned wife. If a man dies who has never married, his family will arrange a 'ghost marriage' with a woman they have selected for this purpose. Bridewealth will be paid to the woman's family, and she will beget her husband's children with a kinsman of his family's choosing (Deng, 1972; Jok, 1999).

## 2.12 Refugee Camps

According to the USCRI (2004) at least one in every five southern Sudanese has died because of the war between government forces in the north and the SPLA in the south. Prior to the signing of the CPA, there was no place to be safe in southern Sudan. The literature offers conflicting information about how the lost boys came to flee to Ethiopia together. The shared narrative presented by the lost boys to the media and NGOs over the years speaks of the boys fleeing suddenly as their villages were attacked, losing sight of their family in the chaos. They then survived by walking the long distance to refugee camps in Ethiopia together (Bixler, 2005; Corbett, 2001; U.S. Department of State Bureau of Population Refugees and Migration, 2001; Zutt, 1994). Another version has also been shared, in which SPLA/M leaders went to villages, and spoke to village leaders of the need to move the young boys to a safer area, so that they would survive, get an education, and be prepared to step forward as future leaders of the country. These boys became known as the *jeish ahmer*, or the Red Army. On arrival at Pignudo Refugee Camp in Ethiopia some of the boys were recruited for military training and served as child soldiers (Derib, 2002; Human Rights Watch/Africa, 1994; Schechter, 2004). Others remained in the camp, and had the opportunity to learn English and focus on education. A small percentage of these children eventually found their way to Kenya, where Kakuma Refugee Camp was established for them by the UNHCR. The majority of the LBLG who later resettled in the United States spent up to 9 years at Kakuma waiting in dire conditions for officials to decide their future (Finnegan, 1999; Jeppson, Nilen, & Tefferi, 1994; Zutt, 1994).

The challenges facing the lost girls were different in many ways from those of the boys. Traditionally, girls are kept closer to home and family for their own safety. While the lost boys received encouragement in their flight to Ethiopia, the girls stayed with their mothers and other kin, fleeing when necessary in family groups. They too experienced much danger. Many disappeared during flight, or were captured and sold as slaves, never reaching the relative safety of the camps (Bok, 2003; Jok, 2001; Matheson, 2002).

On arrival at Kakuma, the majority of the boys were settled together in groups and cared for themselves with some adult supervision, while others chose to join foster families. Of the girls who arrived at that time, most vanished from the official records. Many returned with their foster families to Sudan, or with family who came to Kakuma to find them. Some married and joined their husbands' families. Those who remained with foster families at Kakuma no longer met the strict resettlement criteria for unaccompanied minors. When resettlement began, a relatively small number of unaccompanied girls found their way to Kakuma with the consent of their family. Concerns about gender inequity and disparity in numbers were being voiced by international workers and journalists at Kakuma. As a result, some lost girls were "found" (J. M. Jok, personal communication, November 29, 2006). Ultimately, only 89 girls were found to meet the resettlement criteria and gain admission to the United States compared with 3,276 boys (Duncan, 2000b; Matheson, 2002; Refugees International, 1999, 2002).

## 2.13 Health and Well-Being of Lost Boys and Girls in Refugee Camps

Several studies, all completed at the instigation of aid organizations active in the refugee camps, focus on the mental health status of the lost boys. Each study noted the lack of girls in the camps, and indicated that very few or no girls were included in the research. While some conflicting results are evident, the overall evidence illustrates a population of children who have experienced traumatic events and symptoms related to post-traumatic suffering, yet exhibit strong coping skills and a bright outlook on the future. Taken together, the studies offer a longitudinal perspective of the well-being and psychosocial adjustment of the LBLG.

The Swedish non-governmental organization Radda Barnen (Save the Children) organized interviews with the boys at Pignudo refugee camp in Ethiopia from 1988-1990. Over 13,000 children were interviewed. Two follow-up surveys were completed between 1993 and 1995 with those children who survived the year long journey by foot from Ethiopia to Kakuma following the collapse of the Mengistu regime in Ethiopia in 1993. The purpose of the interviews was two-fold: (a) to gather information that might be used to reunite families and (b) to identify urgent mental health needs of the children. The clinical experience of the mental health team in the camp was also documented. At Pignudo, a total of 173 mentally disturbed children received some form of treatment between 1988 and 1990. This was only 1% of the population of unaccompanied minors at the camp. The Radda Barnen staff working with the children indicated that all of the boys had experienced traumatizing events, including sudden separation from their families and witnessing atrocities committed to their families and villages. Despite these experiences, the boys were doing well both emotionally and physically one year following their arrival

at Pignudo. In a follow up study completed at Kakuma 4 years later, surviving boys spoke of witnessing the death of friends, experiencing extreme hunger, and becoming separated from friends they had lived together with for years. Radda Barnen anticipated that this further trauma and separation would result in increased numbers of mental disturbances. Two years following their arrival at Kakuma, the incidence of mental health disturbance in the children remained significantly low (Radda Barnen, 1994).

A UNICEF team interviewed the children at Kakuma in 1993 to evaluate exposure to trauma and its effects on the youth (Raundalen, Dyregrov, Derib, Juma, & Kaasa, 1994). All of the children were found to have experienced traumatic events. Approximately 50% of the children were found to have symptoms of post traumatic stress disorder (PTSD). Of these children, intrusive memories as well as avoidant behaviors were very common. While the Radda Barnum team stressed the children's ability to cope, the UNICEF team described them as a group in need of extensive intervention because of PTSD.

Radda Barnum sponsored a third study in the hopes of clarifying these conflicting results. Independent researchers were assigned to complete a study with the understanding that they would have complete freedom of design, interpretation of results, and scientific publication. Interviews with 147 children confirmed that all had experienced traumatic events and that many were experiencing symptoms related to post-traumatic suffering. However, these experiences and symptoms were found to have only limited impact on the daily lives and well-being of the children. The researchers suggest that the cultural context of the children's lives, particularly the beliefs and values learned among their family and clan, have provided strengths that have supported their ability to

cope in the face of adversity. Coping strategies identified by the children for dealing with intrusive events included religious practices, seeking comfort from another, playing, or going to school. The children felt supported, with 98% indicating that someone loved them, 97% that they had a best friend at the camp, and 81% that they had a close friend among the adults at camp. The self image of the children was positive, with all able to identify something that they were good at. Ninety percent of the children felt they were living life in accordance with the Dinka values of *cieng* and *adheng*. The children expressed a positive outlook on the future, including their hopes for peace in Sudan and their wishes to help their fellow man. Interestingly, there was no mention of a desire for revenge (Jeppsson & Hjern, 2005).

Results of a study undertaken by a UNHCR team during 1999 and 2000 at Kakuma are consistent with many of the findings of Jeppson and Hjern (2005). At the time of this study the boys, and a few girls, were now teenagers, and most had lived at Kakuma for 7 years. Interviews were conducted with 174 unaccompanied minor and separated children as part of the screening process for possible resettlement to the United States. The purpose of the interviews was to (a) discover the circumstances of the children and (b) make a recommendation for the child's long term best interest. A mental health screening was part of the assessment. All of the children were found to be suffering from symptoms of unresolved trauma and a significant number reported symptoms of anxiety and feelings of guilt. However, symptoms of depression and hopelessness were not common. Interviewers observed that the children living in groups got along well with one another, and that their primary attachments were to their friends. Coping strategies noted included religious practices, most specifically a trust in God, and

a belief that God helped them to survive. The children had a positive outlook on the future, expressing a desire to get an education and then return to Sudan to find their families and to help others. No child had expressed a desire for revenge. The researchers noted only a few girls were interviewed, and these girls had come to the attention of the researchers as a result of the girls' active stance on their right to continue their education and avoid marriage (Duncan, 2000a). To further assess the needs of the girls, active measures were taken to interview girls living at Kakuma. Interviews and mental health assessments were completed with 33 girls, all between 14 and 17 years of age. Nearly half were found to have unresolved medical concerns, including internal injuries resulting from rape, chronic stomach pain from worms, chest pains from overwork, and the more common complaints of malaria and fever. The girls had been placed with foster families, and 24 girls were identified as living in situations which were considered abusive according to the norms of their culture. Sexual abuse was reported by 25% of girls, three of whom reported being raped. Five girls reported being forced to marry against their will, and a further 17 feared early or forced marriage. Like the boys at Kakuma, the girls were found to be suffering from symptoms of unresolved trauma, anxiety, and feelings of guilt. Unlike the boys, nearly 50% of the girls were experiencing moderate to severe symptoms of depression. While several girls reported their religious beliefs provided them with hope to deal with their depression, several girls were identified as being at risk for suicide. The researcher concluded that girls at Kakuma, the majority of who are living with foster families in isolation from their peers, lack the support systems that the boys have been able to create. Without support systems, they are more vulnerable to abuse, neglect, and early marriage. The majority had also been denied access to education,

which was one of the factors which provided the boys with hope for the future (Duncan, 2000b).

## 2.14 Health and Well-being of the Lost Boys and Lost Girls in Resettlement

No studies to date have focused on beliefs and practices related to the health and well-being of the LBLG. Significant risk factors and barriers to care have been identified in older South Sudanese refugees living in the United States (Tompkins, Smith, Jones, & Swindells, 2006; Willis & Buck, 2007; Willis & Nkwocha, 2006). A small but growing body of knowledge has resulted from research focused on their health status since they were granted asylum in the United States. Several studies address the mental health of the LBLG in light of the traumatic events they experienced. In a quantitative study with a convenience sample of 304 (76%) of the 416 Sudanese LBLG enrolled in the US Unaccompanied Refugee Minors Program who arrived in the U.S. in late 2000-early 2001, 20% of the subjects scored in the diagnostic range for PTSD (Geltman et al., 2005). Symptoms experienced most frequently were related to the re-experiencing of traumatic events. High percentages of youth reported experiencing “recurrent thoughts of the most hurtful event” (50%), “feeling as though the event was happening again” (40%), and “recurrent nightmares” (38%). Social isolation on arrival in the United States and a history of personal injury while in Sudan were both positively correlated with symptoms of PTSD. Loneliness or feelings of isolation were experienced by 25% of the children. The children reported a high incidence of seeking health care for symptoms that may be considered somatic within the context of the U.S. health system. These complaints, which have been associated in the literature with behavioral or emotional problems, included



headaches, stomachaches, bad dreams or trouble falling asleep, and anorexia. Despite their experiences with trauma during childhood, these young people exhibited high levels of psychosocial functioning. In a publication presenting further results of this study, Geltman, Grant-Knight, Ellis, & Landgraf (2008) reported that mental health counseling was not positively or negatively associated with functional health outcomes. While high rates of counseling were reported (45%), the rate of counseling use was the same for those who scored in the diagnostic range for PTSD and those who did not. Youth with poor functional health outcomes and youth scoring in the diagnostic range for PTSD were no more likely to seek mental health counseling than the others. However, they were more likely to seek care from any health professional, which includes those who may not have training in mental health care.

A study utilizing qualitative and quantitative methodologies to examine the resettlement experiences of LBLG unaccompanied minors notes that many of the youth reported symptoms of PTSD (Bates, Baird, Johnson, Lee, & al, 2005). Although the authors do not provide specific percentages, they state the mean score of PTSD evident in the children was twice as high as that found in other studies of children who have experienced a single traumatic event. Again, as in the previous study, the symptoms experienced most frequently were related to re-experiencing traumatic events. Qualitative data derived from interviews with the youth and caseworkers provided considerable evidence of resilience. Ninety-eight percent of the youth were in school, and a large majority expressed plans to continue on for a college degree. The group as a whole reported having strong sources of social support, religious faith, and the availability of someone to help them solve problems.

One study examined the past trauma experiences of lost boys currently living in foster homes who arrived in the United States as unaccompanied minors (Bolea et al., 2003). This qualitative study explored the trauma experience as understood by the boys and their foster parents. The children's definitions of trauma reflect a deep sense of loss, with symptoms of trauma containing both emotional and physical elements. One young man shared that "The trauma during migration is like mental illness, pain from the body and starvation" (Bolea et al., 2003, p. 225). The study concluded that to work effectively with the Sudanese refugee youth, it is essential to understand their unique experience of trauma and the meanings they associate with those experiences.

Lustig et al. (2004) describe the process of using testimonial psychotherapy with three adolescent lost boys. The focus of testimonial psychotherapy is on transcribing personal, traumatic events for the altruistic purpose of education and advocacy. It has been found to be a helpful method to allow a voice to refugees who although traumatized, lack experience with, or interest in, psychiatric care. The written narratives that result allow the participants to explore interpretations and meanings ascribed to their traumatic experiences. The narrative of one participant testified to the grace of God who protected him throughout his terrifying journey. As this was a preliminary study focusing on whether this method would be found suitable to the lost boys, data were not collected assessing the efficacy of testimonial therapy in reducing psychiatric symptoms, although the authors cite this as an important next step.

Julianne Duncan (2001), who completed the majority of the best interest interviews with the unaccompanied minor LBLG on behalf of the UNHCR at Kakuma, has gathered information on the adjustment of the youth both 3 months and 6 months

following their arrival in the United States. The results are based on her experiences working with youth placed as unaccompanied minors in Seattle and on reports from program staff from Refugee Unaccompanied Minors Programs throughout the United States. After 3 months in the United States, the youth were all enrolled in school, and the majority had connected with religious communities. Many displayed feelings of euphoria, and reported feeling safe for the first time in their memory. Children placed in cold climates experienced a challenge adapting physically. After 6 months in the United States, some children began to experience symptoms of PTSD, including nightmares and intrusive thoughts. In addition, some began to voice feelings of survivor guilt, which was not common at Kakuma. Many youth were experiencing symptoms of anxiety, sadness and loneliness. There were no reports of acute mental health problems at this time. The population as a whole still appeared to be strong and showed evidence of resilience. Coping behaviors that had been evident at Kakuma continued to be of benefit to the youth. These included a belief in God which provided meaning in their lives, and a dedication to education as a means of helping their people in the future, which provides the youth with a strong sense of purpose.

Goodman (2004) conducted a qualitative study which utilized a case-centered, comparative, narrative approach to explore the coping strategies used by unaccompanied minor lost boys who had been living in the United States for 6 to 12 months. While the narratives speak to the horror of violence, war, and hunger; the children did not present themselves as victims. Rather, their resilient nature was evident as they spoke of themselves as survivors with hopes and plans for the future. Education represented their hope for the future as a means to finding security for themselves and to provide help to

others. A strong sense of community among the boys brought them strength, along with the knowledge that they were not suffering alone. It also provided them with a means to help their peers through the provision of support and encouragement. Examples of suppression of painful memories and feelings were evident in the narratives. There was also evidence that participants were able to find meaning from cultural and religious beliefs about suffering and life itself.

## 2.15 Synthesis of the Literature

Several themes are apparent from this body of research. Significant numbers of LBLG are experiencing symptoms of PTSD, certainly when the symptoms are considered from a Western medical perspective. Yet the majority of studies speak to the resilience of the youth as evidenced by an ability to function well in a new environment. Positive coping mechanisms that recurred in multiple studies were (a) a strong belief in a benevolent God, (b) a strong desire for the education necessary to provide a secure future, and (c) a desire to help those left behind in Sudan. Overall, the LBLG demonstrated a positive outlook on the future. Many have been able to make meaning from their traumatic experiences. While several studies suggested that the cultural context of the LBLGs' values and beliefs may have contributed positively to their ability to cope, there is a lack of research which identifies the cultural context of the LBLG resettled in the United States. In fact, thanks to an impressive anthropological record, much more is known about the cultural context of the lives of their ancestors than of the current generation of LBLG. Cultures do not remain static over time or space. To survive, the culture itself, including belief systems, must adapt to support the survival of the

community. This study was designed to shed light on the cultural context of the LBLG resettled in the United States and to fill a significant gap in the research through an exploration of the culture care beliefs, meanings, and practices related to the health and well-being of LBLGs.

## 2.16 Theoretical Orientation Using Leininger's Theory of Culture Care Diversity and Universality

Leininger's theory of culture care diversity and universality (Leininger, 1991, 1996, 1997a, 1998; Leininger & McFarland, 2002, 2006) will provide the framework necessary to elicit new knowledge related to the domain of inquiry. The theory reflects a synthesis of knowledge from nursing and anthropology which provides a focus on care as uniquely nursing and culturally oriented. Leininger holds that while human care practices and values, specifically how people perceive, understand, and provide care, differ between cultures, there are commonalities about care among cultures too (Leininger, 1996). The two major constructs of culture and care "were conceptualized as being very broad, integrated, embedded, and nestled into each other like an irreducible whole, a gestalt, or a humanistic orientation to life and living" (Leininger, 1991, p.20).

The focus of the theory is on care; indeed Leininger (1997a) states that "care is the essence of nursing and a distinct, dominant, central and unifying focus" and continues to say that "care (caring) is essential for well being, health, growth, survival, and to face handicaps or death" (p. 39). She distinguishes between two types of care, generic (folk) care and professional care. Generic care is culturally learned, is the oldest form of care known, and is essential for the growth, health, and the survival of humans (Reynolds &

Leininger, 1993). Professional care is the formally or informally taught, learned, and transmitted culturally based professional knowledge that focuses on human care (Leininger & McFarland, 2002). Historically, generic care has not been valued in Western institutionalized nursing. It is not unusual for professional care recommendations to be incongruent with generic caring practices. The theory of culture care provides a means to bring the two together in a meaningful way allowing for the delivery of culture care which is congruent with the health care beliefs and practices of the care recipients. Leininger (1997a) maintains that “knowledge of both generic and professional care could prevent cultural conflicts, cultural imposition practices, cultural clashes, and other unfavorable nursing outcomes” (1997a, p.39).

Leininger asserts that there are differences (diversities) and similarities (commonalities or universals) in human care both within and among all cultures of the world. This knowledge is best elicited from the people’s emic, or insider’s perspective as opposed to the nurses’ etic, or outsider’s perspective. The discovery of these diverse and universal care patterns, meanings, and expressions will provide nurses with the knowledge they need to guide professional decision making and actions which support health and well-being. All discoveries made are discussed collaboratively by the researcher and informants to confirm their accuracy, ensuring that the researcher is accurately representing the insider’s perspective. Leininger has identified three modes of action and decision making which reflect the nurse researcher’s thinking, planning and use of emic data from informants to provide care that promotes health and well-being. The modes of action are identified as (a) culture care preservation or maintenance, (b) culture care accommodation or negotiation, and (c) culture care repatterning or

restructuring. The three modes allow for mutually agreed upon decision making and action with regard to both generic and professional care. When creatively used and thoughtfully developed with the care recipient, the modes of action and decision making lead to the provision of culturally congruent care, which is the goal of the theory (Leininger, 1991; Leininger & McFarland, 2002).

Leininger's background as both an anthropologist and a nurse is evident in the Sunrise Model Enabler, which she developed to provide assistance to the researcher, and provide clarity between the concepts put forth in the theory. The Sunrise Model Enabler provides an overall picture of the major dimensions or interrelated components of the theory (Appendix 1). It functions as a cognitive map, which depicts the cultural care worldview, social structure dimensions, environmental context, language and ethno-history as they influence and are influenced by culture care and health. The enabler provides visual evidence of Leininger's belief that human beings can not be separated from their cultural background and social structures. It also reflects her ideal that culture care transcends the individual to be inclusive of families, communities, and society. The Sunrise Model Enabler guides the nurse in the discovery of culture care knowledge and in the application of the knowledge in ways that are meaningful within the cultural context of the care recipients. Linkages and influences between the concepts are clearly evident, particularly between the three modes of nursing care decisions and actions and culturally congruent care. Leininger's (1991) Sunrise Model Enabler achieves its purpose of depicting both abstract and concrete aspects of the theory "whose goal is to discover inductively and explain, interpret, and predict culture care knowledge and its influencers in order to understand and develop ways to provide culturally congruent care" (1991,

p.49). Without this strong transcultural focus, cultural imposition practices may occur, resulting in frustration, loss of trust, and lack of caring from the perspective of the person requiring care.

## 2.17 Summary

This section compared and contrasted the contributions to the literature which explore the ethnohistory, culture, health care beliefs and practices, health and well-being, and lived experiences in African refugee camps and following resettlement of LBLG living in the Midwest United States. Given their history as unaccompanied minors growing up amidst war and famine, it is not surprising that much of the research has focused on the mental health of the lost boys. This research indicates that significant numbers of LBLG have experienced trauma and loss, as well as the symptoms of PTSD. What remain unclear are the meanings which the LBLG ascribe to health, well-being, and care, as well as the professional and generic caring practices which they consider to be beneficial to their health and well-being.

An overview of Leininger's theory of culture care diversity and universality, which provided the theoretical framework for this study, was presented. As discussed earlier, Leininger (1997a) has indicated that one of the major tenets of the theory of culture care is that "there were differences (diversities) and similarities (commonalities or universals) in transcultural care knowledge and practices that awaited discovery to establish a body of relevant transcultural nursing knowledge as the new guide to nursing practices" (p. 35). In reviewing the nursing literature, there have been no published research studies focusing on the culture care knowledge, beliefs and practices of the



LBLG of South Sudan, either in the context of Sudan or any of the many countries to which these young people migrated. One would expect to find some forms of caring that are universal among their practices, but would also expect to find some diversities.

The next logical step is a qualitative research study designed to elicit the meanings and practices related to health and well-being within the LBLG community. Research focused on teasing out the emic perspective of similarities and diversities among the professional and generic (folk) beliefs and caring practices of the LBLG is necessary to further our understanding of and meet the health care needs of these young people.

# Chapter 3

## Methodology

### 3.1 Ethnonursing Method

A qualitative ethnonursing research method designed to gain an understanding of culture care beliefs, meanings and practices related to the health and well-being of Sudanese LBLG refugees was used for this study. The ethnonursing research method was designed by Leininger to fit the theory of culture care and obtain emic data which will allow greater understanding of informants' lives. For Leininger, the relationship between the researcher and the informant is vital to the process of teasing out and gaining understanding of generic, or folk, health care meanings, beliefs and practices. To be successful in this process "necessitates that the researcher enter the informants' world of knowing and learn from them about their knowledge and practices" (Leininger, 1997a, p.42). Ethnonursing emphasizes the direct, personal involvement of the researcher with the people within the community with the goal of utilizing nursing theory, methods, and practices to obtain nursing data (Brink & Wood, 2001; Leininger, 1998).

Leininger's ethnonursing research method was ideal for this study because of its fit with the theory of culture care. It is well suited to discovering and understanding the differences and similarities between generic and professional nursing care among different cultures. Knowledge and understanding of the current cultural beliefs and values

about health, well-being, and generic caring practices of the LBLG will assist nurses in utilizing the three modes of nursing action to provide them with meaningful, culturally congruent care.

### 3.2 Mini-Study

The researcher conducted a mini ethnonursing study that sought to begin to identify, describe, and analyze the culture care beliefs, meanings, and practices related to health and well-being of the lost boys. Further purposes of the mini-study were to evaluate and refine the research questions, methodology, and the semi-structured interview guide developed by the researcher; and to prepare the researcher in understanding the emic perspective of the lost boys in preparation for progression to this larger ethnonursing study. In the mini-study, four key informants and eight general informants were interviewed with the use of an open inquiry guide developed by the researcher to elicit emic data related to the domain of inquiry. Ten of the young men were interviewed in their own apartments, and the remaining two in a private room at the community college where they are students and the researcher is on the faculty. All of the general informants were interviewed once. Three of the key informants were interviewed twice, and one only once because he moved out of state before a second interview could be completed. Key informants were identified as such because of the richness and depth of the knowledge they shared related to the domain of inquiry.

Numerous generic (folk) beliefs and practices related to health, well-being, illness, care, and treatment were explored through observation and participation within the community, and semi-structured interviews with the lost boys. Three emerging but

not clearly-defined themes were identified from the mini-study. The lost boys identified the ability to contribute to and meet the expectations of the community as necessary for the maintenance of health and well-being. Spiritual care, grounded in a belief in the strength and wisdom of one God, was found to be health promoting and illness preventing for the lost boys. Honoring the values of respect, dignity, presence, and confidentiality was found to be central to the meaning of care (Bowles, 2005). While the mini-study served as a good first step towards filling the gap in the research, it had several limitations, including (a) lack of data saturation, (b) failure to include young women, (c) limiting informants to those who identify themselves as Dinka, and (d) limiting informants to those who live within narrow geographic boundaries.

Leininger and McFarland (2002) assert that a mini-study is the ideal start for a novice transcultural nurse researcher wishing to gain skills prior to completing a larger ethnonursing study. Completing the mini-study did result in the acquisition of many new skills. It also helped the researcher to establish rapport and trusting relationships based on mutual respect within the lost boys community. The mini-study raised new questions and avenues of thought related to the health care beliefs and practices of the lost boys. Emic data speak to the significance of the role of women in the provision of care, highlighting the need to include the voices of lost girls in this study. The emergence of a theme identifying a relationship between the ability of the lost boys to meet the expectations of the community and the maintenance of health and well-being requires further exploration. While the political and social context of the lives of the LBLG within the United States must be explored further, a more global perspective focusing on the political context of the LBLG within the South Sudanese diaspora is warranted. This ethnonursing study with

the LBLG population was designed to better understand the phenomena discovered in the mini-study, and to explore further the culturally derived beliefs, meanings, and practices related to health and well-being of LBLG refugees living in the United States. This knowledge will be essential for nurses who strive to decrease the risk of cultural imposition and minimize the special health risks in the LBLG community.

### 3.3 Context of the Study

This study was conducted in the homes and communities of LBLG refugees, primarily within, but not limited to, the Midwest United States. This setting was chosen because the researcher works and lives in a Midwestern city which is home to one of the largest populations of LBLG in the United States. While completing the mini-study in preparation for this study, it became evident that the members of the LBLG community are quite transient, often moving between cities based on job or educational opportunities, and connections with friends and family. The community did not define itself as LBLGs living within specific, narrow, geographic boundaries; rather it defined itself within the much broader context of LBLG who live in the United States and Canada (Bowles, 2005). The community context for this study included informants' homes, churches, schools, social and political gatherings, as well as community health care settings.

### 3.4 Entry into the Community

The researcher is well known in the South Sudanese LBLG community, and has been actively involved with the community dating back to their arrival in the United States in November 2000. At that time, the researcher was completing a practicum at the

refugee health clinic of a local county health department, and the LBLG made up the majority of the population seen at the clinic. Upon learning that the researcher taught nursing at a local community college, a large number of Lost Boys arriving at the refugee health clinic spoke of their desire to further their education, and asked questions about enrolling in college. In response to this, a two week orientation program was designed and offered at a local community college specifically for this group of young adults. Many began attending classes the following semester, and came together to form an active Sudanese Student Organization. The researcher was the faculty advisor for this organization from its inception. Upon learning the purpose of the mini-study discussed earlier, many requests were received from students within the LBLG community to participate in the study. Concerned about a potential conflict between the roles of faculty advisor and nurse researcher, the researcher instead asked for introductions to other community members who were known to have in-depth knowledge about health care beliefs and practices. Several of these LBLG were educated and employed as health care providers at Kakuma Refugee Camp, and served in leadership roles within the community. They were eager to share their knowledge related to health care beliefs and practices within their community.

Leininger's Stranger to Trusted Friend Enabler was used in the mini-study to continually assess and analyze the relationship between the researcher and the lost boys' community as the researcher strove to move from stranger to trusted friend (Appendix 1). It was also used in this ethnonursing study as a tool to evaluate progress from stranger to friend as new relationships were formed. The Stranger to Trusted Friend Enabler encouraged careful observation and self reflection on the part of the researcher during the

data collection phase of the study, which was essential in the formation of trusting and caring relationships. A trusting relationship is a prerequisite to obtaining authentic, credible and dependable data (Leininger, 2002).

### 3.5 Informants

Leininger maintains that 12 to 15 key informants and 20 to 25 general informants have been found reliable to reach saturation of data in studies using the ethnonursing method (Leininger & McFarland, 2002). The researcher interviewed 4 key and 8 general informants for the mini-study. For this maxi study, saturation of data was reached after interviewing an additional 7 key and 10 general informants, bringing the study total to 11 key informants and 18 general informants. Data from the first interviews guided the researcher in identifying key informants, who demonstrated expertise related to the domain of inquiry. General informants represented the wider community and were able to provide data that is reflective of how their beliefs are similar or dissimilar to those of the key informants. Community leaders and key informants who participated in the mini-study assisted the researcher in identifying further informants for this study. This snowball effect is culturally appropriate within the Sudanese community where relationships, both business and personal, start with introductions from family or trusted friends. All who were asked to participate in this study accepted. Two of these potential informants never met with the researcher. One was unable to meet because of the demands of school, while another moved on short notice to celebrate his marriage in Australia.

When inviting informants to participate in the mini-study, the researcher explained that interviews would last approximately 1.5 hours. It quickly became apparent that this was an unrealistic time frame, and that informants would determine the length of the interviews. Key informants demonstrated expert knowledge related to the domain of inquiry. All of the key informants responded in great detail, illustrating key concepts and meanings with stories and detailed examples, and as a result interviews averaged between 1.5 and 2.5 hours. For this maxi study, 2 key informants were interviewed three times, 7 were interviewed two times, and 2 were interviewed once. Second interviews were as long as the first, while third interviews focused on specific points of clarification, and were much shorter. General informants were interviewed once with interviews between 1 and 2 hours in length. Criteria for selection of informants included (a) identifying oneself as a Sudanese “lost boy or girl” refugee, (b) being over 18 years of age, (c) resettling from Kakuma Refugee Camp in Kenya to the United States in November 2000 or later, (d) the self reported ability to speak and understand English, and (e) willingness to participate in the study and be interviewed.

### 3.6 Data Collection

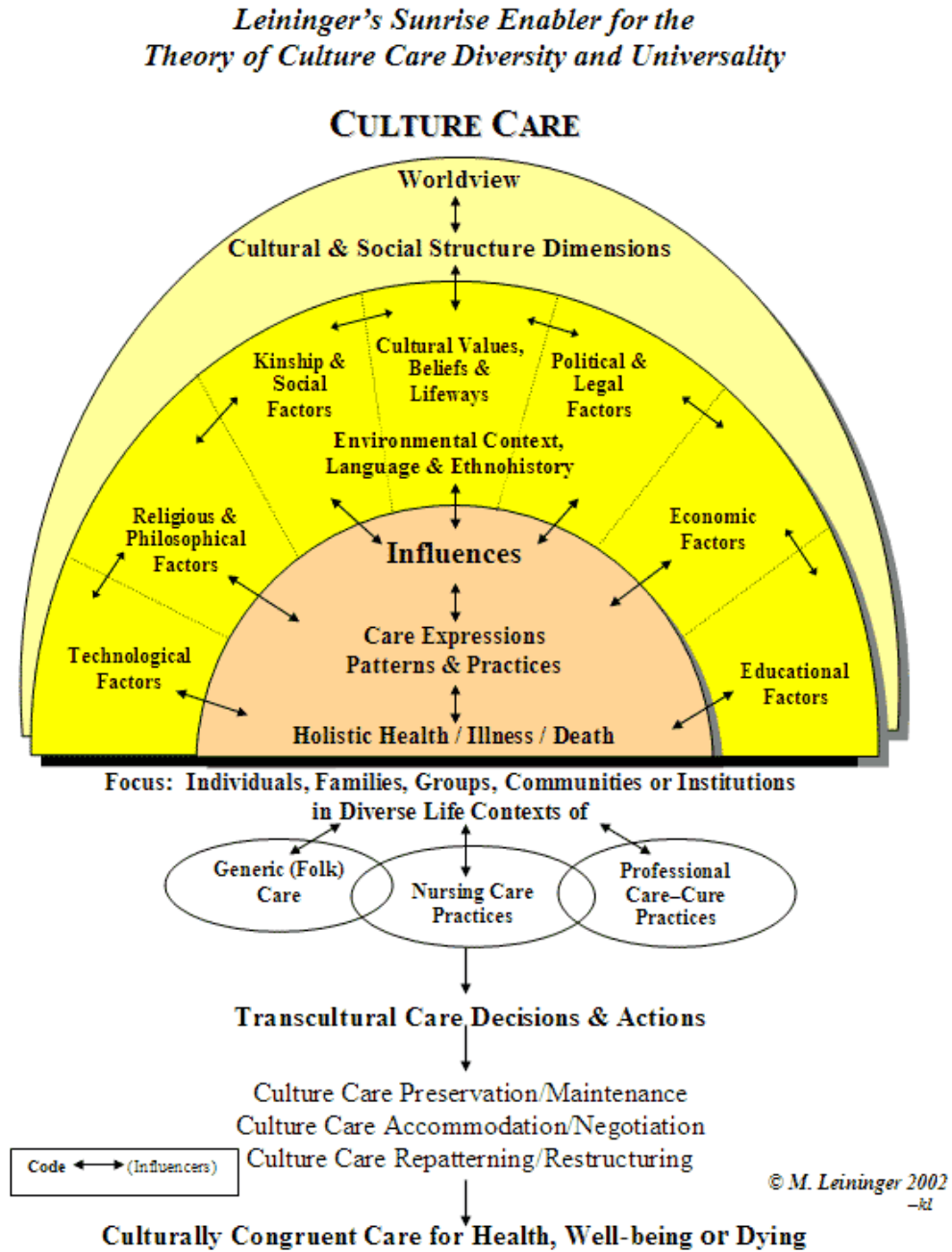
Data collection included participant observation with field notes, photographs, and audio-recording as appropriate. Interviews were completed with informants in a place of their choosing, in environments that were familiar to them. At the start of the interview, the researcher explained the purpose of the study and obtained a signed consent for participation in the study and the use of a digital recording device. A semi-structured inquiry guide, developed by the researcher based on the culture care theory,



was used to obtain a full and detailed account from the informants of their culture care beliefs, meanings and practices related to health and well-being (Appendix 2). Digital recordings of the interviews were transcribed by the researcher and/or transcriptionist who was fully informed of how to maintain the confidentiality and security of the recordings and the information contained on them. When the recordings were transcribed, all identifying information about the informants was deleted.

The Sunrise Model Enabler was used to assist in teasing out the cultural and social structure dimensions of the LBLG, and identify beliefs, values, practices and care meanings, both generic and professional (see Figure 3). The Sunrise Enabler was developed by Leininger (1997a) as a conceptual theory guide and enabler that “focuses on multiple care influencers (not causes) that can explain emic and etic phenomena in different historical, cultural, and environmental contexts” (p. 40). The enabler encouraged a process of open inquiry, allowing the participants to begin sharing in the areas where they have the most knowledge and/or interest, while cuing the researcher to direct them to areas that had not been covered. The enabler allowed the responses of informants to guide the data collection process, as opposed to a rigid interview tool which would have kept the focus of the interview solely in the hands of the researcher. The Sunrise Enabler served as a constant reminder to the researcher that the goals of the study were to obtain the worldview of the informants (top of the enabler) and identify how that influenced care expressions, patterns and practices (center of enabler), and finally how that knowledge can be used to develop and provide culturally congruent care for health, well-being or dying (bottom of enabler). Interviews were considered complete when saturation of data

had been reached and no new data were emerging. Interviews were transcribed immediately in preparation for analysis.



*Figure 3*

Leininger's Sunrise Model Enabler

### 3.7 Human Subjects and Ethical Considerations

The researcher described the study to each informant, and obtained written informed consent. Informants were asked to read the consent form, and the meaning of each section was verbally clarified. Opportunities were provided to ask questions during the review of the consent form, and at completion. The consent form included information about the details of the study, risks and benefits of participation, right to withdraw, and assurance of confidentiality (Appendix 3).

Ethical considerations related to data collection focused on honoring the privacy and dignity of the informants. To protect the privacy of the informants, all digital recordings, transcribed notes and field journals were kept in a locked drawer in the researcher's office and will be destroyed after all aspects of the study are completed. Transcribed data were pseudonymous and free of identifiers. Digital recordings, transcribed notes and field journals were only used for the purpose of data analysis. The importance of confidentiality and securing the digital recordings and transcribed notes was reviewed with the transcriptionist. The transcriptionist was required to read and sign a confidentiality agreement to ensure the confidentiality of all informants and the data accessed through transcribing the digital recordings (Appendix 4). Informants were made aware that a psychiatric-mental health clinical nurse specialist was available should they become distressed during the interview and require an intervention. Informants were informed that they have the right and freedom to withdraw from the study at any time. Permission to conduct this study was obtained from the Duquesne University Institutional Review Board.

### 3.8 Data Analysis

The researcher analyzed the field notes and transcribed interviews as soon as they were available for emerging patterns and themes related to the concepts of health care beliefs, meanings and practices using Leininger's (1991) Four Phases of Ethnonursing Analysis of Qualitative Data (Appendix 5). In the first phase data were collected, described and documented, in the second phase descriptors and components were identified and categorized, in the third phase emerging patterns were analyzed, and in the fourth phase the researcher abstracted major themes from the data. Identified patterns and themes were clarified during follow up interviews with informants. Data were continuously processed and reflected on. Leininger asserts that "this process of data analysis is detailed and rigorous but essential to meet the criteria of qualitative data showing how the researcher met the criteria of credibility, recurrent patterning, confirmability, meaning-in-context, and other criteria of a qualitative study" (Leininger, 1991).

Coding and data management were assisted through the use of QSR N6, a software program developed for qualitative data management by QSR (Qualitative Solutions and Research) International. QSR N6 was previously known as NUD\*IST, an acronym for the accurate description of Non-Numerical Unstructured Data Indexing, Searching and Theorizing. N6 was designed as a toolkit for the coding of text documents, including transcripts of interviews, field notes, personal interpretations and reflections. It was also designed to assist in the process of analyzing and reviewing the coded data (Richards, 2002). The researcher's observations of the informant and his or her environment, as well as the researcher's reflections, thoughts, questions, and feelings at

the time of the observations or interviews were entered into N6, allowing for easy access to this data. Each item of data, including the transcribed interviews, was coded with the date of the interview, the number of the interview, an informant code, and a code which identifies where the data collection occurred. Data were coded in accordance with the categories and domains from the culture care theory. Nodes were created to store each category and domain in N6. Additional nodes were created as necessary to capture and organize all available data. Guidance was sought from the chair of the researcher's dissertation committee during the process of data collection and analysis. Identified patterns and themes were clarified during follow up interviews with key informants, and are presented in Chapters IV and V.

### 3.9 Summary

This chapter described the methodology, context, sample, data collection and analysis, and ethical considerations for this ethnonursing study which was designed for, and used in, the discovery of culture care beliefs, meanings, and practices related to the health and well-being of South Sudanese "lost boy and lost girl" refugees living in the Midwest United States. The study built on preliminary discoveries resulting from a mini-study the researcher conducted in preparation for this study. Leininger's Culture Care Theory guided the researcher in uncovering in-depth knowledge and understanding of the worldview of the LBLG, and in learning directly from them the significance of their beliefs, experiences and values surrounding human care, health, and well-being. A total of 18 general and 11 key informants were selected and interviewed for the study, at which point saturation of data was reached. Ethical considerations related to data

collection focused on honoring the privacy and dignity of the informants. Leininger's four phases of ethnonursing analysis of qualitative data were applied to analyze and synthesize the emic view of the LBLG in relation to the domain of inquiry, resulting in authentic, credible and valid data. The findings of this study added to transcultural knowledge through the discovery of the cultural context of the LBLG and the influence of the culture on beliefs, meanings and practices related to health and well-being, which are discussed in the following two chapters.

# Chapter 4

## Results and Findings

### 4.1 Introduction

This chapter presents the findings from interviews with key and general informants as well as observations of the environmental context in which the interviews and other interactions with the informants took place. The findings were derived from the emic, or insider's perspective, as well as the etic, or outsider's (researcher's) professional views and observations. The researcher's participation in a variety of community, social, religious, political and educational activities within the LBLG community also contributed to the findings.

Data were initially transcribed verbatim from digitally recorded interviews. Although all of the informants spoke excellent English, it is not their first language. The rhythm, grammar and cadence of speech they use, influenced by their education in British English and their experiences with English speaking aid workers of different nationalities in the refugee camps, can be confusing to those lacking familiarity with it. As a result, the original transcriptions were altered very slightly to adjust grammar and syntax and to allow informants' voices to be better understood. All data presented here are direct quotes from the participants with minor grammar adjustment. To protect confidentiality,

pseudonyms have been used in place of the names mentioned by informants during interviews, unless the name refers to a public figure.

A total of 11 key informants and 18 general informants (see Table 1) were interviewed for the study, which is consistent with the ethnonursing method. Interviews were continued until saturation of data was reached. Interviews were conducted at a time and place chosen by the informants. While only the researcher and the informant were present for the majority of the interviews, interruptions were common place as friends and roommates arrived and stopped to offer greetings. The interview was stopped until visitors left or the informant asked that the interview continue with friends within earshot.

Twenty-seven informants were male, and 2 were female. The researcher had limited access to “lost girls,” because only 89 girls and young women were admitted to the United States compared to approximately 3,800 boys and young men. Since it was not the practice to record a specific date of birth in South Sudan, the birth date of individual LBLGs was often a best guess, based on the approximate age of the individual when he or she fled his homeland. Official ages, which were often considered inaccurate by informants, were determined at Kakuma during the interview process with the UNHCR.

All but one informant shared January 1 as their official birthday. Several know the year or season of their birth but not a specific day. Recording birth dates is not common practice in rural areas of South Sudan. On resettlement to the United States, a default date of January 1 was provided by the Immigration and Naturalization Service. The year of birth stated by the informants varies from 1978 to 1987.

All of the informants identified themselves as LBLG. Of these, all but two identified themselves as Dinka, which is the most populous ethnic group in South Sudan.



One informant identified himself as Nuer and one as Bari. Informants were born in several different regions of South Sudan, with the majority coming from Jonglei. Other regions of birth included Bahr El Ghazal, Equatoria, Upper Nile, and Bahr El Jebel.

Nineteen informants identified themselves as Christians, without naming a specific denomination. Of the remainder, four identified as Catholic, four Episcopalian, two Lutheran, and one Christian Reformed. Three of the informants were married, and 26 were single. Two informants had children.

## 4.2 Presentation of Categories

This section presents the second phase of Leininger's (1991) four phases of Ethnonursing Analysis of Qualitative Data which consists of the identification and categorization of descriptors and components (Appendix 5). In the first phase, data were collected, described and documented, in the third phase emerging patterns were analyzed, and in the fourth phase the researcher abstracted major themes from the data. Data analysis was initiated in the mini-study and continued until the end of this study. The researcher began by coding and classifying data related to the domain of inquiry and the research questions identified for the study. Initially nine *Tree Nodes* were created in QSR N6 qualitative data management software. These *Tree Nodes* served as containers for organizing data according to categories, all of which correlated directly to dimensions of the theory of culture care. During the process of data collection and concurrent analysis, eight additional tree nodes were created as further categories emerged from the data. Emic descriptors were studied within context for similarities and differences.

Categories identified from the data analysis which correlated with the cultural and social structure dimensions of the Leininger's culture care theory and reflect the worldview of the LBLG were environmental context, kinship and social factors, cultural values and lifeways, religious and spiritual factors, economic factors, political and legal factors, educational factors, and technological factors. Additional categories that emerged during data collection were meaning of health, meaning of well-being, maintaining health and preventing illness, health care seeking behaviors, barriers to care, experiences with professional care, traditional healing practices, and generic caring practices. A full description of these categories, supported by data from the LBLG and the observations and field journal of the researcher, are presented here.

#### 4.3 Environmental Factors

When describing their life experiences, the majority of the informants contextualized these experiences within the environment they were moving through or living in at that time. A shared narrative emerged, with the beginning and ending of separate stages of their lives marked by descriptions of place as much as events. In the telling of history, the specific environment itself came to mark a specific stage of childhood. The environments experienced as very young children in Sudan, primary school-aged children in Ethiopia, and teenagers in Kenya were described as being different from one another in terms of habitat, vegetation, climate, shelter, safety, food, people, health care, and educational opportunities. All of the informants noted stark differences between the environment in the United States and those in which they grew up.

While informants' narratives of life in refuge focused on several aspects of their environment, the scarcity of food was the primary focus of all informants. An informant gave an example of how he survived through the most difficult time, although others died of starvation:

We came to Paschala when we'd done with that river; there was no food for like two months. People were eating leaves off trees; we almost got the whole of them done in that area, but fortunately the UN came by and we had a little something to eat.

The availability of animals for slaughter decreased because of the effects of famine and war. Meat from slaughtered animals was saved to eat later rather than eating it all on the day of slaughter. Informants noted that this increased the likelihood of sickness.

Another informant noted that food was not always scarce when he was growing up before the war:

The only reason I got here was because there in Africa, all the food that we eat is natural. They don't use any chemicals there or fertilizers. They don't use those. They just only cultivate them with just only rain and after they harvest them and then they eat them like that. But here we've got everything like chicken they put in the freezer, and meat in the refrigerator, like that. It might stay like 2 weeks to 1 week and only there they just bring the goats and they kill it. And then they eat it fresh.

The environment at Kakuma was described as a hot and dry. The soil was not good for growing crops and the water supply was limited, yet many informants noted that they grew what they could. One informant described his normal eating pattern at Kakuma, and how he has since returned to the meal patterns of his childhood before the war:

Here is the normal pattern of the boys here. And it is like, you get up in the morning, you don't worry about breakfast. Go to work, and when you come back by noon, you have to eat. Then you stay for the whole day, maybe at 9 pm at night you eat and then you go to bed. That was the pattern that people have been doing back in Sudan. When I came to Kenya, because of the shortage of the food, we have to eat only once a day. That means you have only to eat at 9 pm.

When invited to conduct interviews at informants' homes in cool weather the researcher noted that the thermostat was often set above 72 degrees F. Curtains were usually kept shut, resulting in a hot, darkened environment. Many informants said that they did not like winter because of the cold and snow, but were getting used to it now. Some remembered their pleasure the first time they saw snow. Several others spoke of friends who had relocated to states with warmer climates, including Texas, Arizona, Georgia and Tennessee, where they could join communities of LBLG and escape the cold.

Several informants noted the problem with obesity in the United States, and expressed concern that it could become a potential problem in their community:

Variety in food is very important. It is not just a matter of eating. And like here, the American foods, I've really seen that some [Dinka] people are even growing bigger and bigger, and that's become a problem now. It makes some people fear that they will also be that big [laughs].

Many informants referred to challenges they face because of differences in the economic environments in the United States and Sudan. Traditionally their families grew food, fished, and enjoyed meat and milk from their herds. They built their own housing, and had no need for money. While living in the refugee camps life was very difficult, but no monetary payment was required of them. One informant voiced the frustration felt by many other LBLG as they adjusted to a monetary economy:

Sudanese, when they were back home, nobody owned the land and you don't have to pay for living expenses, you don't have to pay for rent, you don't have to pay for food and all these kind of things. But here in America if you don't have money to pay for living, for food, then you have no where to live, you will not even exist, that's the life.

Informants noted that the high prevalence of disease experienced when they lived in Africa was influenced by the climate: "There was not much rain. People were always

living in dry areas. And some people get chronic malaria because of the sun and flies.”

Another informant explained, “There was no water, like no good water. So now here we got good water.” All informants noted differences in the quality and availability of health care between Africa and the United States.

In Africa mostly the weak and diseased, you know, there is nowhere you can go. Even if you go to the clinics, you can not get much help, so it is better for me to just stay in my house and pray for the God to help me because even if I go there I know I’m not going to get the help that I might want, like I would if I go somewhere in the U.S.

American culture was viewed by the informants as having both positive and negative qualities. They appreciated the opportunities for jobs, education, and security, as well as meeting and learning from people from other cultures. One young man expressed what this level of security meant to him:

It is a lot different here; you can not even imagine how big a difference it is. Number one, what we eat, it’s a big difference. Number two, I send some money to my families so they can eat, some can go to school, some can go to the hospital, so they’re not thinking about a lot of stuff; it’ll make a difference. Another difference is I know some American friends here a lot and they teach me a lot of different cultures too here. And the living standard here too, I have a job; I can go to school as I want, so it’s really a difference.

Yet the majority of informants also expressed concerns about the effect American culture was having on some of their peers, particularly those who arrived in the United States as minors.

The environment is fine, it is good but in this environment we live and do a lot of things. Crime is affecting people, especially in the Sudanese community here. And availability of beverages like alcohol and all these things have become a major factor that is affecting people right now.

Another informant noted the potentially negative effects of what is shown on TV and how that may be affecting some of the younger LBLG:

While watching the TV, every time I see all the rappers, and dancing, and all these ways of life on TV . . . It’s the way they make their living, it’s not the reality

of life. And, the young people take it, “This is life.” So, this is what happens to the young people.

Several informants described experiences in the United States which resulted from prejudice and discrimination based on their black skin color. Their responses to the situations varied from ignoring the incident if it was considered minor to dealing with it as a community when it was considered critical. Many informants spoke of their pride in being black, and of a need to speak out if others do not treat them with respect because of their skin color. A young informant asserted,

I’m proud for me being black. And I always say we all wear different colors. The color you’re wearing, the color of the shirt you’re wearing right now, you’re not going to wear the same thing tomorrow . . . God might have done that for everybody. He might have created people differently for his own pride to look beautiful, to make the world look beautiful. So I don’t really like feel bad for me being black. I’m really proud for being black . . . It’s different for some people; how people express that you are different from them. So there’s a difference with me being black and how a person said it. If a person said it wrong to me, then I have to react to it in order to explain to him so he can understand. “There’s a difference why you’re white and there’s a difference why I’m black.” And that comes to the point where there is a difference or there is a miscommunication between the two people. I have to explain for that person that he wasn’t in his right mind to call me that name, not calling me black but another name. Or it’s not right for me to call that person a different name because we shouldn’t be doing that.

Several informants described incidents where they felt they were victims of police profiling. One young man noted that

The police here, the police have different views. There are police who have understanding of certain social community and there are police who have this like simple judgmental way of seeing the people as black, and just say pretty much, even though you are a black who is not associated with that black culture they will think that yes you are black and that is typical of what you do.

These negative experiences with police were balanced somewhat when leaders in the LBLG community invited a local police chief to attend a community meeting to answer questions and learn more about their culture. Several informants shared their pleasure that

the police chief attended and listened as leaders within the LBLG community explained some cultural differences, particularly related to child rearing and marriage. Informants who attended were particularly impressed when the police chief praised strengths that he had observed in their community. One informant who was present at the community meeting described the experience:

Some boys lose their job because they are drunk and they go to jail and they are fired. We do not need that. Like last month ago, we have a meeting here with the Police Department. They are trying to convince us, because they say don't adapt to this culture. "Do not drink . . . you do not have bad credits. You are good people because you call all the people and let them listen to the police." That is how that made us to be a strong community. Some other community has not called them but we call them and we talk to the government. We respect ourselves. We are a strong community.

#### 4.4 Relationship between Environmental Factors and Health and Well-being

Loved ones back home are never far from the minds of the LBLG. While much of the context of their lives has changed, they remain mindful of the challenges posed by the environment in which their friends and family are living their lives. A key informant provided an example of the feelings of guilt he experienced soon after his arrival in the United States.

When we came here to America it was kind of different . . . . For example myself, when I came here, and I got food, I refused to eat for some days because I was saying that there are some people that I left behind, they don't have some to eat and I have some to eat now.

LBLG spoke of coping skills which allow them to thrive despite their knowledge of the hardships that remain in their villages and communities at home. An informant provided an example of how he avoids thinking too much about the cycle of loss and suffering:

I think when I have something in my head, I will go to friends and then we'll talk. From there I will be alright or I will go to work, or look for something in TV and watch. From there I will forget. So I don't have to disturb my mind saying oh, oh, unless some people call then say, "Hey, here's what happened, so and so died, so and so died." It has become normal to me now, but it's not normal to the younger boys. If they heard, they'll say, "Oh! I just talked to him 2 days ago, and he's died?" Like I just heard the day before yesterday my aunt died and I said, "All right, that's fine" and another kid was saying, "What, are you mad?" I say, "Why?" "Why did you just say it's alright?" I said, "What can I do? She is dead, there's nothing I can do. What I can do is just send them money and that's it, and I'm going to do that. So what else am I going to do?"

Adjusting to the challenges involved in learning to use modern appliances, purchasing and cooking food that bears no resemblance to the animals or vegetables that they once were, driving cars, finding jobs, dressing for extreme temperatures, and trying to figure out why Americans behaved as they did, were all described by LBLG as early stressors that impacted their health and well-being. In the first year following arrival, the four young men whom the researcher worked with as a volunteer sponsor, were responsible for a total of nine car accidents. As children, they never experienced the learning that comes from crossing busy roads or traveling as passengers in cars driven by parents or other adults. The foundational knowledge gained from such experiences had to be learned along with knowledge of the Highway Code and the technical skills of driving a car. Sadly, several LBLG have been involved in fatal car accidents.

A sense of living in isolation has plagued many informants, who lived in close quarters with other LBLG throughout their many years of exile. While the INS and refugee resettlement organizations attempted to resettle boys in the same living groups as existed in Kakuma, this did not always happen. Typically lost boys had shared living quarters with eight to ten others at Kakuma, but could not continue to do so in the United States because of caps placed by landlords or city ordinances limiting the number of inhabitants who could safely occupy a specific apartment. On arrival, most lost boys were



grouped together with four in an apartment. As they started working different shifts and attending classes, it wasn't unusual for them to feel isolated, since they were not accustomed to being alone. A key informant noted the loss of social interaction that many experienced as a result of living in this environment:

Since you are living alone in your apartment and you are the only person, you are everyone in the house, so you can actually do anything that you want and that maybe is going to be your downfall. So of course it is not benefiting us because culture is tough and the culture here is tough . . . The fact that you wake up everyday, which actually we are not used to according to our culture, to wake up everyday and expect yourself to leave the house, it very rarely happens in our culture. Most of us were born in the farm, in the villages and the life we had before in the [cattle] camps was a great life. I mean it is not great to the extent that it is always healthy, but social interaction was very high.

Many LBLG are experiencing long term health effects which resulted from the environmental conditions they lived with as children. Several informants spoke of illnesses affecting members of the community that resulted from exposure to contaminants found in water or food. Others noted that they were malnourished on arrival in the United States. A key informant described the type of situation which has contributed to chronic health problems among the LBLG:

Some people bored water holes in Africa. And you go to the water hole and get some water. So you don't know what is there in the water. So you come and cook food with them and drink them. So you can get stomach ache and a lot of worms maybe. And some people here are living with those now, and have, you know, stomach pain.

#### 4.5 Kinship and Social Factors

Circumstances related to of the selection of individuals granted resettlement in the United States as refugees from Kakuma strongly influenced the demographics of the LBLG who settled in the midwestern United States. These demographic characteristics

have in turn influenced the social arrangement of the lives of the LBLG today. Those whose documented age was less than 18 at the time of arrival received the full range of child welfare services as non refugee children living in their communities. These benefits continued until they reached the age of 18 to 21, depending on the limit set by their state. The majority of arriving minors were initially placed in foster care families. Many struggled with the sudden separation from the friends and kin who they were living with at Kakuma. Some of the youth were unhappy with these arrangements and were allowed to live in apartments with groups of their older peers, sometimes staying with foster families during the week while attending school and spending weekends with older peers. The monthly child welfare payments they received helped to pay the household expenses of the group they were living with, which was appreciated by their older peers, many of who earned only minimal wage. An informant, who was initially placed with a foster family, shared that the LBLG who arrived here as minors had diverse views on which was the best living arrangement:

I was asking to be transferred out from foster care to independent living. And some of my friends in North Dakota were asking to be transferred from independent living to foster care. And they were complaining that we were told in Kakuma that there is a family who is waiting for you. So when they came and they were placed by themselves they were shocked. And they said, "Where is the family that you promised us? You know we've been staying for all these years without a family so we need to see that sense of being in a family." So it was a big thing. So Sudanese, you know, it depends. Some of them like to be more independent, and some of them like to live in a group.

Many informants described the traditional living arrangements of extended family which they experienced as children in their home village. When couples marry, they move to the village of the man's family. The Dinka and Nuer have traditionally been polygamous societies, and the majority of informants referred to their fathers as having more than one

wife. Two informants spoke with pride when speaking about the roles their fathers held as local chiefs, sharing that they had sufficient wealth to support many wives.

#### 4.5.1 Kinship Ties

A strong sense of kinship ties, both within the local south Sudanese community and with family members scattered throughout the diaspora, remains important to the LBLG. These ties go beyond living relatives to reflect respect for their family line.

Several young men spoke to the benefits that come from the obligation to maintain the honor of one's family:

Sudan is so big. And even sometimes Sudanese don't talk a lot about their differences. But we have a lot of similarities as well as differences too. And we have all these dialects, different geographical locations and they teach children slightly different ideologies. But the bottom line is you have to be loyal and be patriotic to your own origin, your place of origin. And you have to protect the history of your family. You have to excel to raise the name of your family. And that's what guides a lot of us because you don't want to bring any bad name to your family although they are not there for you. You still have the respect for doing far better, to continue keeping that name positive. So that's a big thing and that's why I see a lot of boys excelling more and doing so good because they want to continue that legacy of their family line.

Several traditional practices that reflect the importance of this family legacy are continued by the LBLG in the United States. Several informants were able to name the originator of their clan, and recited the names of their ancestors going back seven or even ten generations for the researcher.

#### 4.5.2 Elders

The family structure and role expectations of Dinka and Nuer youth provided training from an early age in the responsibilities expected of a community elder. There is a system of hierarchy within the family structure, with older siblings fulfilling the role of elder to younger siblings. From a young age, the oldest brother is responsible for the

safety of younger brothers who are in his presence, while older sisters hold the same responsibility for younger sisters. As they get older, the responsibilities increase. A key informant explained:

Let's say for example, like I'll be an elder to my brothers. Like now, when I take the floor they will all give me their full attention when I talk because they know that whatever I will say will not harm them or will not fail them in any way. Whatever I will say will benefit them. So when I take the floor they will all be patient and they will listen to me. The elders of the Sudanese community, you don't have to be 70 years old or 80 years old. You have to be a little bit or even a year older.

When asked about the role of elders in the LBLG community, informants consistently emphasized that elders are valued members of the community, and deserving of much respect. One informant described the use of story telling by elders to inform and provide direction for those with less experience:

The older people, especially the old men, the elders, their job is to teach young people stories, stories of their history, stories of their economic status, stories of their political participation, stories of their heroism, you know stories of loyalty and stories of success. They don't talk a lot about negativity or failure. So they very much concentrate only on their achievements. And that's one part of the history that sometimes tends to lean on one side, because the Sudanese don't like to talk about negativity so they always focus on the positive thing. So stories teach people; it's just like they give hidden meaning to go and reflect on your own. So when elder persons sit and try to share stories, he or she will try to give you a general overview of what they know, or how they can see that you can shape the community. Like when we left (Kakuma) a lot of us were armed with steps, mostly advice from the elders to go and learn skills and come back and help our people.

There are formal Sudanese organizations made up of elders in South Sudanese communities throughout the United States. Individuals are selected based on their leadership skills and their ability to resolve issues of concern in the community. One informant described the role of elders in his community in the Midwest United States, pointing out how the role of the community elder differs from that of the church elder:

Some elders are men and some are women. In a community, if they have any problem, the elders call together the committee. And where do they get a place where the people can meet? They come to the leaders of the church, and say we need to have a meeting on this day. The church elders can talk to them about the meeting they would call and what was the meeting. They will tell the church elders it is because “we got to do this and we need to solve this problem.” The church elders will allow them. They bring together the community elders and the church elders. They do the same to the people. That is what I mean about our strong community.

The vast majority of informants expressed an obligation to share what they are learning as a result of living in a different society and through the pursuit of higher education with those who remain in Sudan. Several noted that this is resulting in a change in traditional roles, with elders asking for and accepting advice from those much younger than themselves. The elders may reflect on the advice, and consider it in the context of the lives they are living. An informant described the impact of such change:

And even today, a lot of our elders are changing their old traditional beliefs. The children know more. The children have the other side of world experience so they tend to listen to them more. They understand the other cultures and whatever that they will say is in conjunction with their own culture. So when I talk to elders, like when I went home, I went to Africa twice, and when you talk to a group of elders they will tend to listen to you because they know you have explored more. You have accomplished a lot. So they tend to put you in that category of giving positive inputs. And they would take those seriously. And then they would internalize it and use them with their own experience and elaborate on it more.

#### 4.5.3 Gender Roles

Informants also consistently spoke of how much gender roles have shifted over the course of just one generation, which is certainly not unique among resettled refugee populations. What is unusual is that on arrival, this refugee population consisted almost entirely of young men, with very few women, children or elders from their own culture present as they established themselves in the United States. It is only very recently, as they begin to marry, that some of the young men have begun to live in family units.

Unmarried men living together in apartments typically share housekeeping tasks among themselves. Traditionally these chores were the responsibility of women and girls, but most lost boys have had no choice but to do them themselves. One informant emphasized to the researcher that he would not be cooking if he were in Sudan, and several mentioned they will no longer need to care for the apartment after they were married. To do so would reflect badly not only on themselves, but on their wives, who would lose respect for not caring for the family as they should. An informant explains:

Like in my culture the man cannot cook. That is very, very important. If you go to the kitchen and cook and your woman sees you she will tell you, “You know what; I know you shield me a lot. I will not allow you to cook. If you want to cook all the time, okay, I’ve got to leave you. You cook by yourself.” That is one big trust factor there; that is why a man cannot cook.

Traditionally women were responsible for teaching their daughters the roles that they will assume when they marry and have children. Girls stayed close to their mothers until they married and left home. Informants, both male and female, described how the girls stayed with their mothers whenever possible during the war, fleeing with them when situations became unsafe. If a girl lost her mother, another woman from her extended kin would take care of her, and look out for her safety. A male informant explained:

The women, they run away with their mothers. And when we came to Kakuma, we were being grouped separate from our sisters or the girls. So the girls were living with their mom or foster parents. Some people they don’t have parents, but they can go and stay with different ladies that can teach them how to do things, because men don’t have more responsibility. So women are the ones having more responsibility than men. Women know how to cook. Women know how to clean. Women know how to take care of kids. And that’s why they try to teach the young ladies how to become a woman in the future.

There have been many questions in the Western press about why so few lost girls were resettled in the United States compared to lost boys. Many informants, both male and female, noted that girls were expected to remain close to their family for protection, while

it was usual for young boys to venture farther away. Many informants explained, without being asked, that fewer girls ventured to Kakuma and left Sudan because it was not normal for girls to be apart from the family before marriage. A female informant explained the rationale for this:

Mostly, in Dinka, young women and girls are not supposed to go far away from their parents, and be on their own. A boy can go, and do those things, and there won't be any big issue. But young girls, it's like, they are there to be safe. They're being protected. You hear the adults say, "Don't go there," and "You can't do this." And so, some girls didn't come. They were with their families, and their families, then, think, like, "Oh, it's not safe for my girl to go there by herself, in this different world. I have no idea where they would be. They have no one there, know nobody." But the thing is, the family might see some positive in sending boys out. They might be like, "Oh, okay. This is what men do. They explore the world. They go everywhere." But, like, "This is what women do. They take care of the families, and be there to bear children, and be a good mother.

Several informants shared that it is unusual for men and women to eat their meals together. The researcher observed this at several community events, where the women and girls brought food to the church, which was then set out potluck style. Men served themselves, and then congregated together at tables, while the women and children gathered together at other tables. A key informant who had invited the researcher to one of these events explained why this occurred:

The reason why they did that is when we eat together, and when I have visitors in my family, my kids will not pay respect to the visitor. So when people are eating, my wife will not be okay when somebody eats there in the family and she eats together with them. No, she will not be eating good. So that's why we have that for the women to go and eat by themselves. Sometimes when the ladies talk and when men talk, then it will be rare for the lady to talk where the men are because they are very shy. They need to have their own place so that they can talk freely and when the men are there, they don't talk.

Education was not as high a priority for girls in much of rural South Sudan as it was for boys. Several informants noted that while some girls focused on getting an education while at Kakuma, there were many who dropped out early because their chores

had to come first. Many girls were betrothed in marriage while still in their teens. This has changed for many of the lost girls and young women who resettled in the United States. A young man explained how many lost girls are focused on education in the United States, and putting off marriage to a later age:

Right now the top priorities of girls are going to school; this is something that we try to let them know. If you're 18, don't get married, because that was back then. Now you can go up to 25 and be still fine. Imagine getting a degree at age of 25 and everybody will look after you, but they don't seem to understand. So, there's a culture thing that tie in with the age situation but other than that people are changing so it's not going to be a problem in the near future.

Female informants lived with foster families upon arrival and did not seek to move into a group apartment. A female informant explained that her family back home does not consider it acceptable for a young woman to leave the safety of a home before marriage. She remains at the home of her foster family while attending a local college, which is no longer the case with any of the male informants, who are sharing apartments with their peers or families. Another female informant lived with her foster family while attending high school and through her first year of college. She moved into the dormitory at a small liberal arts college as a sophomore student. She shared that she first sought advice from her family in Sudan who trusted her judgment that this was the best place for her to be, near college resources like the library, which will increase her likelihood of success.

Another informant spoke of the role fathers have in raising their sons and how important it will be for him to do the same for his future sons:

I can't let my culture get lost just like that. The values that I consider most powerful, is how to be in bond with your father. The part of bonding as a male, I suppose I learned a lot about culture from my father. However, I can share both; I have an obligation to learn from my mom. But my mom did not have a lot because she didn't learn anything from her dad. She was always bonded to her mom; there is a separate group here. There's mom tying with the little children,



little girls but dad always looks for his sons, trying to let them know about the culture. So, we really have a lot to offer when it comes to fatherhood . . . they teach us how to be dependable, they teach us how to be strong, how to be motivated in life.

## 4.6 Cultural Values and Lifeways

### 4.6.1 Obligation to Family and Community

Obligation to family and community is an important cultural value within the LBLG community. The extended kinship network that provided the context for their lives when they were children has been dispersed as a result of the war. While all informants spoke of losing close family members, including parents and siblings who died during the conflict or while in exile, they also spoke of kinship networks which remain vital today. Many informants spoke of traveling back to Sudan to meet with family who never left or returned from exile:

When I went back to Africa I was gone for 3 months. And when I was gone for 3 months, I wanted to see everybody in my family, they were all scattered. So my dad was inside Southern Sudan where I call it a war zone. When I went back there, I got my parents, my brother, with his little kids and his wife and I spent a little time with them and some family and I have got a lot of cousins as my grandpa was a chief and he got nine wives. So I've got a lot of cousins!

Another young man who had been separated from his mother at the age of 4 or 5 described how he is renewing a connection with his mother across the distance:

I didn't see my mom for quite some time and I know from the bottom of my heart that she is the one that gave birth to me and knowing that in the top of my mind made me realize that without her I wouldn't be existing today. At home we didn't really spend some time to get to know her personally but I feel the need, knowing that I have been through all that made me do more than just help. I have to call at least twice a week. I have to make sure people are in good condition.

Obligation to family goes beyond maintaining close relationships and offering advice. What belongs to one family member belongs to the community, and is shared

among those who are in need. Every LBLG spoke of sending substantial portions of their income to relatives who remain in Sudan or neighboring countries. Many are sacrificing their own financial security in the United States in order to ensure the safety and security of their extended family. One young man noted,

If there is money they need back home, I'll give it to them. My mom, I rent them a house in Nakuru, in Kenya, another city called Nakuru. My sister is in the school, my brother and my mom stay home. So I have to pay rent for them, I pay the school fees for my brother and sister, and that's what I've been doing with money.

Another informant described a similar set of responsibilities:

I'm responsible for the whole family, extended family. Like my grandpa had like three wives. And those three wives, one wife having four kids, five kids, six kids. And all that extended family I'm responsible for it, plus the other friends, plus the other friends that are friends to one of my people in my family. Plus the families-in-law that my uncle married to them or like my dad married from my uncle, brother to my mom. Other relatives that are close to my mom's side, I need to support them. If somebody came to Kenya or Uganda so that they can reach me by calling me by the phone, and if I have any money, I need to send some money to them. Now, my uncle who is there working in New York is doing his own part. Like if one of my families got me and then I send money to her or to him, then I call Uncle and say that I sent money to so and so, so that he will not send money to the same person. That is the way we balance it now.

Traditionally kinship obligations have been reciprocal, and that remains true today. However, an inequity exists, with the needs of those in Sudan much greater, and the resources much fewer, than those of the LBLG. An informant with a wife and infant son in Kenya explained that he is contributing to his family's support in Africa yet knows that they will do all that they can to support him too. Knowing that his family is looking after his wife and son gives him hope, and contributes to his sense of well-being:

Like the work I am doing now, I am supporting my family. I am not supporting only my wife and son; I am supporting some others as well there. I know that they are in a bad situation, because Sudan is not in a good situation and they are in the refugee camp and some are in a displaced [person's] camp. They are not in a good position and they are not in good life. I have to support them. The reason why I support them, I hope that I will see them in the future and also I have a hope in

my heart that if I am away, they can take care of my wife and my son, because we are family. This is in the culture, our culture, your relatives around, you have to support them. You are born not only for your father and your mother, you have to support everybody. You have to help . . . and in the same way they can help me too. For example, if I want now to move back to Africa and I want to live in Sudan, what would I do? I cannot just go there and just rent a house. They can prepare everything while I am away. They could tell me that “You know what, it is good for you, to live in this city,” and they can prepare everything for me over there. But in food, like here I am making money here, so I can do that and that is the way the community can do things together.

Several informants addressed the conflict that they experience as they try to balance their own needs with those of their extended family. Families are aware that the LBLG have jobs, drive cars, and have TV sets, all signs of wealth. Many can not understand why there is limited money to send. Many informants described the stress and sadness they experience when they are unable to meet their family’s expectations:

When we came, a lot of us were like 18 and above and we have so many things to catch up on. And also with this age of us, we need to do things for ourselves and other people, and sometimes one hand cannot clap. That is why some people have this stress because, I want to help this family, and I want to help that family, but all the help comes through one paycheck. Also, we have another life over here that they don’t see. They don’t think that we have to go to hospital and then pay money. They don’t think that we buy a car and then pay the insurance, they don’t think that we buy the gas, they don’t think that we pay the rent, and all some other expenses, they don’t think that we go to school and then pay our own school fees. So, with all this stress, the other side doesn’t know it, but we all know. So, if you try to explain and they don’t get it, it sometimes leads to like, hey, what can I do?

Another informant, who is working full time while attending college full time, pointed out a connection between meeting family obligations and maintaining one’s own health:

Sudanese lead a collective way of life, whereby your parents, your relatives, wherever they are, if you are in America they depend on you. They say we have this so and so in America and he is the one to provide us with you know this and so you receive a call from there. From here you feel that obligation that it is your responsibility to fulfill their needs while your needs are not fulfilled. So it gives people a lot of those kinds of, you know, problems outside of finance . . . people may not have the time or money to save to treat themselves or to take care of their health, like dental problems and kind of like you know some other minor things that you need to take care of.

#### 4.6.2 Marriage

The traditional system of marriage, which remains the norm among the LBLG, is very complex from the perspective of an outsider. Given the age of the lost boys, the scarcity of young Dinka and Nuer women in the United States, and the expectations of LBLG and their families that they will marry, marriage is a topic that is never far from discussion. An unmarried informant seeking an advanced degree shared that his family had expected him to be married before now. He stated that

Marriage is not a personal choice in my culture. It is something that all of your relatives, they come and they sit down, they say it is time for you to get married. And then you have to do that. The people who are coming after you, like some of your brothers, they need to get married. If you don't get married, people will have to wait until you get married, according to seniority. Until the older brother gets married, and even the daughter too, they have that system, and that makes it very hard.

A large number of informants shared that their family is encouraging them to begin the marriage process soon. Others are married, with their wives living with family members in Africa as they wait to receive the necessary clearance from the INS to immigrate to the States. When asked how they met their spouse, two of the married informants shared that their family members initiated this process, while the other met his wife while living at Kakuma, and asked his family to arrange the marriage. Diverse opinions were offered about which is best. Several informants shared that either way is acceptable, as long as both families support the choice. An unmarried man explained his view:

A long time before we went to school, before we leave our village, the family decided who is the husband of the lady, of your daughter. And since we started going to school right now, we are deciding now, who do you want to love? What kind of lady do you like, what kind of man does she want? So, we change from the traditional where the family picks the lady for the son, and most of us right now, we're looking for the girl that I like, that my family likes. But before that, our family picks the ladies for us. That was the traditional life, an arranged marriage. And in my generation right now, it's kind of changing.

One informant offered a very detailed description of how many LBLG continue to marry in the traditional manner, with some necessary adaptations to accommodate the process of selecting a spouse and the betrothal itself over a vast distance. The process is very similar whether the family selects a woman for the young man to marry, or the young couple decides first, and approaches their families for permission. Several steps are involved, with family members of both young people researching the background of the potential spouses and their extended family to make certain that everyone involved will be a credit to the family they are joining and have the ability to be good spouses and parents.

Approaching the marriage, first of all you have to have a friend, a girl who is a friend to you or girlfriend. It is up to you and it is up to your dad and your mother to know exactly where you are heading. They have to make sure that they know who we are dating, but it is not actually that you should tell them that this is whom I am dating, because it is a culture of respect. You cannot cross the line and talk to your mom and dad as if they are like your age mate. So someone that will know them well, like your cousins who are at the same ages as you are and your brothers at the same age . . . they can determine who is a good lady to be your dating lady. So once they know that, then the culture has different steps towards the marriage. When you want to get married as a guy in your family, the family has to come together first and gather and try to discuss who it is you are marrying. If it happens while you are away they can still do it. When you are away they will consider you as a part of the meeting. So the discussion will tell who is the right person for you to marry. The second step, you and the guy of the same age, your cousin and you, will first go and try to review the lady that you want to marry. If you are not there then your age mate has to go and do that same thing . . . And then they will interview the lady about the marriage and at the same time the lady would have other age mates, the girlfriends that she has, and this group will interact and will actually bring something into the discussion. Then once you are accepted, then the girl will take the kid to her parents. Now everything is most important in the second step to the third step. The family of the girl, will say, "Okay welcome them." If you are welcome then you will go and celebrate, bring the dance and do something to show that you want to have this relationship. If you are welcome to the family, then you are allowed to have your dance celebration and then the family who has the daughter will hold a meeting afterwards to see if you are legitimate to take their daughter and the whole family of that girl will try to get that and then they will vote at a meeting. Well, some will vote against you and some will vote in favor of you. So if you passed that stage then actually your

relationship is accepted. At that third stage, all of these things can happen if you are present or when you are away. So everyone, any of your relatives can do all of that, even if you are not there. Then that will be final stage whereby you have to go and take the girl with her girlfriends and cousins to spend like 3 days or 7 days and then they can return later to their homes. So that is the final stage and this is when you have your wife now with you. But you know that is your wife, it starts from the time when your relationship becomes accepted by the family, when they did the voting. So that day, even though you did not take her, she is considered to be your wife no matter what . . . So before the meeting of the family to decide whether your relationship will be accepted or not you have to pay the dowries. Your dowries plus the way you are actually trying to impress everybody about who you are . . . and your family background, all of these will actually tell their decisions. So they will tell you, it is like having a GPA or a SAT score and all that, so they are trying to know much about who you are and then make the final decision.

From the above description, it is obvious that marriages are not undertaken lightly. The process is long and expensive, complicated by many challenges that are unique to the distance over which the negotiations take place. Informants spoke of the difficulties involved when communicating by phone across time zones. There is a small window of opportunity when both parties are awake, and with many LBLG working long hours, they may have to take time off work or school to make an important call. Some spoke of waiting weeks or even months while a family member makes a trek to a distant village, and informs the family of a prospective bride that the suitor is eager to speak with them. A family spokesman then has to travel to a village or town where a phone is available, and remain there until they can reach the suitor by phone. The challenge doesn't end here however. The young man, speaking from the other side of the world, now has to convince the family that he is a suitable man for their daughter. A recently married informant whose wife remains at Kakuma shared his feelings about the competitive nature of this experience:

It is very challenging, because when you are doing this and you are this far away, pretty much, most people do not know who you are. Of course they will know your family and when she brings this, your whole family is going out to

campaign. So it is exactly like the campaign trail in America when you are going for any political position. And it is difficult because you have to keep up most of the time. You have to be polite enough. You have to tell the truth and you have to be concerned with what you are doing because everybody is going to throw any bad questions at you and you have to be patient enough and take the right question. And you should like to try this test about whether you are going to be a great husband to their daughter. That is exactly what they want to see and everybody is not going to be nice to you in the beginning. It is like when you answer as a presidential candidate about health issues and Medicare, and Medicaid, and war and all of this and they will see how you will take the question and the same thing they will ask you about some of the other social things, about what if . . . And they will go back far to your family background, whether somebody has divorced back before and then what are you going to do because you have this record.

There are further challenges as the LBLG move towards marriage. All of the male informants spoke of the exhaustion experienced when working multiple jobs to save money to provide the bridewealth for the family of the woman they were courting. The dollar equivalents of cows are so great that it is almost impossible for one person to save it on his own. Informants explained that when friends are preparing to marry, others he shares an apartment with may cover the cost of the rent, and his friends and relatives here will contribute what they can to help him gather the necessary funds. The understanding is that once he is married, he will contribute to the cost of bridewealth for those who were close enough to help him. Even so, the expense is daunting. An unmarried informant, who recently landed his first professional job following graduation from university, expressed concern at the prospect of raising the money necessary for marriage:

Yeah it is a burden actually. For example, some of the lost boys are now of marriage age, some of them they go back and marry there in Africa. And they pay millions of shillings, which is thousands of dollars. Marriage, especially marriage in Dinka communities, marriages now cost about \$25,000 to \$30,000. And that's very, very expensive, you know. That's what you need to give as a dowry or something like that. But including the process of getting married, it will go up to \$40,000 or \$50,000. This includes the process where you will get your parents together, you're calling all the time, you call your parents, and you call your in-laws and all this. Whoever needs to talk to you, you call them and whoever needs

help for transportation you give money, for transportation to Sudan or to Kenya to Uganda to wherever and it's kind of like very, very hard.

Family members remain the best sources of financial support as the LBLG contemplate marriage, especially those who live in the West. The family of the prospective bride may allow for a payment plan if they are very satisfied at the prospect of a marriage. When discussing bridewealth, one informant shared that

The family of the girl would say okay, now Jok, we like you, you're a good man; you can give us 20 cows right now. And in the future when you are good with our daughter and have the kids you can pay more; bring more than the 50 that you are left with. And the uncle or son, which are in America or somewhere other where like in Australia, Canada, they will contribute to my marriage. They will pay whatever it will take for them to let me get that lady. So they will support me financially, they will support me, if they have a cow back home. If they don't have any money in America, they will say, I have my mom who has three cows. I'll take two of them to your cows, and then they will add them on to your marriage. Those are the support you can get from nephew from cousin, from distant uncle, whoever.

Another informant, while agreeing that some financial support is provided by relatives, indicated it is never enough:

That system is not in place right now because you know people don't have cows anymore, because of war nobody has. So you are the one who is getting married, you are the one that has to pay that thing.

The vote of support from both families as they give their consent to the marriage and agree to the offering of bridewealth is a stabilizing force in a union. The young couple has the satisfaction of knowing that their families feel positive about them both, which can add to feelings of confidence and self worth. An informant explained some of the benefits:

It is the best time, as we know marriage is really nice and the good part of it, it tells how parents are confident about who you are . . . it has some benefits because you are not the one doing it alone. When you are facing a problem it is not you alone and when you are happy it is not you alone, everybody is happy. So that is it basically and everybody gets a share. And that brings everyone together and then that is like bringing two families together as one. So it is very beneficial



in that way. It is telling you that you can depend on your in-laws from both sides, the other family and this family, and it is not like you have just pulled them together. It is them that were trying to see whether there will be a magnet to each other or not . . . So it is like when you know that they are coming together, you know that they trust you, and it is not you bringing them, just bringing them together, but their trust and your trust and the two of your trust bring everyone together.

#### 4.6.3 Divorce

Divorce among the LBLG is rare. An informant explained that one of the benefits of having both families evaluate the prospective couple before the marriage is that they can determine then whether the marriage will be good or not:

When a marriage has reached the final stage that means that everybody has done something, and everybody is a part of it. And after that, it is not you alone divorcing now. It is like the two families coming together to agree whether to divorce or not.

Family members, who wish a successful union for the couple, will put pressure on them to resolve their differences. If a divorce does occur, bridewealth must be returned, which is a very complex process. Bridewealth may have been sent as cash; some as cattle from family members, and sometimes cattle that was purchased with money that was sent from kin in many countries throughout the diaspora. When a divorce occurs, the many members of the woman's extended family who received bridewealth must return it. It then must be redistributed to the man's family, with every individual who contributed a cow reimbursed. If children are involved, the process is even more complicated. Several lost boys shared that returning bridewealth today is almost impossible to do across the distance. Money which was sent may have been spent to meet the needs of the woman's family in Sudan, and cows remain in short supply following the war. As a result, most failed marriages among the LBLG in the United States result in separation rather than divorce. A young male informant noted that

When you are married in Sudan with cows and then you come here and get a separation, people don't go for any divorce, because when you get divorced there is nobody to pay your cows back. In Sudan when you divorce, if you have five kids, your five kids will be covered with some cows, and some cows will go back to you. But here in America, you will end up with nothing, you can just give up . . . A lot of the boys who know your wife wants to leave you, you just end up in separation, that's all you can do.

#### 4.6.4 Children

Children are cherished in Dinka and Nuer communities, regardless of whether they are living in South Sudan, a refugee camp, or the United States. As mentioned earlier, honoring and continuing the family lineage is an important aspect of the culture. Children represent the future, and families have traditionally been very large. The researcher was repeatedly told that children are cherished, that a woman will hope to have many children, and that children are cared for by the entire community. These statements were validated on many occasions as the researcher participated in events and celebrations within the LBLG community. Young children were frequently present at church services, weddings, fund-raising events, graduations, and clan gatherings. When a child began to cry because of a fall, there was always an older child or adult there to pick the child up and provide comfort. When a parent was called up to speak or to join a dance, his or her child was scooped up by someone else. If one child was seen quarreling with another in the absence of parents, a nearby adult or older child stepped forward and dealt with the situation. A young man shared that

When you go to a Dinka tribe now, you cannot find a homeless child or a child on the road, it's very rare. And it is the culture that they are being brought up by family; everybody is responsible for the children. Like in the absence of their parents, there should be relatives there, and if there are no relatives, there should be somebody close to them, you know, that could be involved in that. So it is like that, and it is very good.

Traditionally families are large, and many children are expected. The majority of informants shared that they hoped to have large families. Only two informants, who were among the youngest interviewed, suggested that family size may be limited if they were not able to earn enough to support a large family. Both acknowledged that this may not be an acceptable option to many of their peers. One of these young men explained why it may be acceptable to limit the size of a family in the United States, and why it was never necessary to do so in Sudan.

We cherish kids a lot. As Sudanese and as a community, we love kids and we want to have a lot of children. If you're in America and if you ask me if I'm going to have kids someday, then I want to say OK, if I have 20 kids, then am I going to be able to afford them? It's a different way than being over in Sudan whereby if I have 20 kids, then I can send some of them to my dad. They can stay with my dad. And dad and mom will take care of them while also they can take care of grandpa and grandma, if they are old. And here in America, as a dad, you have to pay for their school. You have to pay for their health until a certain age. So it has an impact. And you have to decide the number of kids you're going to have. How are you going to support those? I don't know about other people. But that's how I can look at it. And if I'm going to have one kid, and that's because I'm going to support only that one kid compared to like if I have two and I'm not going to be able to support them, then there's no need of having it. So it really depends; in coming to U.S. a person doing that. But I don't think women have ways to say that I'm going to only have one kid. And I think that's something that you should be discussing before your marriage. In America now you have to do that. But if we are in Sudan, then that's not something you really want to bring up. Because if I'm getting married, then she knows that we're going to have kids.

While children are cherished, they are not spoiled. They are expected to be polite to visitors, to show deference to those who are older than themselves, and to reflect well on their family and community. When children misbehave, they are disciplined in accordance with the seriousness of their misdeed. One informant shared, "Child rearing back home in Sudan, especially in South Sudanese culture, it is very different than here. Here you have to, you know, just to yell at the child and all that, and you don't touch him

or her.” When girls misbehave, they are usually disciplined by their mothers, and boys by their fathers. According to a young male informant,

If a girl does a mistake their mother has the responsibility to discipline them. Their father contributes too but not a lot. And it may sound different, but that’s how it is. Anybody can interfere if they did a mistake in the absence of the other person, in the absence of one of you, mother or dad. If the mother was absent, their father could take action to discipline the girl no matter what they say. On boy’s side, it is the same too.

A system of hierarchy related to the age of children within families grants older children some responsibility in counseling and disciplining younger siblings of their own gender.

The way in our culture, my younger brother cannot get married before I get married. And this is the way that we were brought up. He has to respect my seniority as an elder brother and the same I have to respect them that way. And if we were still like at the age of maybe 15 downwards, and we violate, you know, we can be beaten at that age. They consider us at that age, if any of us is behaving badly, they have to be disciplined, you know. As an elder brother, when my younger brother misbehaves, I have the right not to harm him; I have a right to, as an older son, to discipline him or to discipline them, the boys.

When a child misbehaves in the community and family members are not present, those who are present have a responsibility to teach that child that their behavior is not acceptable.

When you see my child doing a mistake or crime in my absence, and although you are not a family member, you have to discipline them. Because it is for everybody to discipline the kids, you know . . . so long as the crime or the mistake they made is a very big mistake, you can even have a right to beat them and show them that you don’t have to do this.

When the researcher asked about disciplining children, responses were always long, with informants taking great care to explain that there were many different ways of disciplining children, but for more serious offences beating a child is necessary. One informant used an analogy of growing a strong tree to explain the need for serious discipline:

If you cannot beat your kids, they will grow as animals. That tree outside, before it is like this one [showing it drooping to the ground]. If you put it like this one [straight and tall], it will grow that good way. But if it starts growing this way [drooping to the ground], later on if it grows, it starts breaking this branch and this branch, it will never happen.

When discipline is necessary, an explanation is usually given to the child so that he or she will learn what they did wrong, and why it is not acceptable. A young man explained how this is done in his community:

Even they don't just beat them and let them go. Later people bring them down and sit them down and bring the mistake they did and show them, ask them like an interview, "Was it good what you did? These and these and these?" and telling them that "No, it was bad. So next time you cannot repeat a mistake like that."

Many other options were offered for disciplining children:

The way they could be disciplined is not only to beat them, but they could be punished for a short time, not a long time. Their food could be set out in front of them and they cannot eat it, depending on what mistake they made. They cannot see other persons. Or if a stranger comes by and they talk badly to the stranger, there could be a punishment for that, based on that mistake they did. If it was within the family, if it was for example a fight among the children, that could be treated differently than if they were misbehaving toward the other person from a different family, from outside. It is a serious case if they misbehave toward other people because, you know, in our culture we believe that to mistreat a foreigner, you can be easily cursed because of that one. And you can be cursed by what your children did. If they do a mistake and they're at a very young age, people believe that may stay with them until they get their own kids around and that can be transferred onto their kids.

The researcher was informed of several instances within the LBLG community when Child Protective Services were called in following a complaint by a neighbor, or a teacher at the child's school, claiming that a child was abused. As more LBLG get married and start families, this is becoming a great concern to the community. One local South Sudanese congregation recently invited the police chief to meet with community members to discuss areas of cultural conflict. One focus of discussion was concerns around disciplining children. Several informants who attended indicated that the

conversation was helpful, but the conflicting values about the best way to raise children remain a concern.

As discussed earlier, elders are highly respected and maintain an important role in the community. They have earned the right to receive good care from their children. One informant stressed the reciprocal nature of the relationship between parents and their children, and how they care one for the other at different times in their lives:

Elders do not have to be on their own. They have the right to be treated well and to be taken care off like they took care of people before when they were little. And that is why it is important to treat children well, or they will not be in a good situation and later on you will be under them, taking care of you.

Several male informants attended classes on arrival in the United States and became certified as nursing assistants. One of these young men, who currently works in a nursing home, described the responsibility adult children have in providing the best care possible for their parents:

That one [care] is very good in our society. It is very good care. We don't have a nursing home or something like that, but you have your kids. When you are old enough that you can no longer support your life alone, your boys and girls, they will care for you.

Married sons and their wives take turns caring for the sons' parents. The hierarchical system within families provides a clear structure for sharing this responsibility. Another male informant describes how this system works:

What we do, like in my family, I have three brothers and I make four. So what we do as a family or as a community, the boys stay home . . . Like if my older brother gets married, then he stays home until I get married. And then he moves out. And then I stay home. And then when my younger brother gets married, then I move out. And then he stays home with mom and dad. And when the last one gets married, then the other one will move out. And then the youngest he has to stay home with mom and dad. Unless there are some issues between him and his family and mom and dad, then us brothers we have to sit down and say OK, what can we do about this? If there's something that we can do about it, then we can do it. If there's nothing we can do about it, then he has to stay home and take care of

mom and dad. And then we can come and visit, see how they're doing. That's how we do it.

#### 4.7 Religious and Spiritual Factors

All of the informants in this study identified themselves as Christian. While some of the LBLG had been baptized by Sudanese pastors while living in their home in Sudan, the majority of the LBLG converted to Christianity during their time in refuge. Several of them described the experience of being baptized while at the refugee camp in Ethiopia.

Here is an account of one man's experience:

I'm a Christian, but when I was born I was not a Christian. I was born traditional like where my mom, my parents were, they were traditional. They believe on animal, they believe on trees, they believe on Sun. We can say it will be rain tomorrow; those are the things that we believed before the war came to our town. In 1987, when the war came to our village and everything was destroyed, that's the time I was turned to be Christian. Somebody came to us and said, you know, there is somebody who created you, there is a God, and from that time he teaches thousands of the lost boys. In 1988 that is when a lot of the lost boys were baptized to be Christian. That's the time that everybody would say "Okay, how can you survive this jungle without anything? There is a God."

When asked about religious beliefs and practices during their early childhood in Sudan, it became evident that the experience of placing one's faith in God was not a new concept.

This was emphasized by an informant who wanted to be sure that the researcher understood that belief in God was an important part of his traditional belief system. He said slowly, clearly, and with a strong voice, "Before all this there was a God that people believed in too." Several informants described clear memories of their family praying to God. One informant described situations when his family would turn to God for support:

Well, it's like where I came from, especially in Sudan, before we even knew the creator which is the God, we also speak of God. So, when something happened, like a child is sick or cows are dying or something like that, people will tend to do some rituals or performance. But before they even do those they have to call God,

believing that He is there and He will make it happen . . . within my family; we have some other idols but sometimes if dad or mom chooses to call these their own God, they are allowed to do so.

Participants shared many stories from their life experiences that first led them to place their faith in God. While the experiences were shared as examples of God's strength and goodness, they were also offered as evidence of the strength that participants experience from knowing God, regardless of the outcome. This particular story was shared by a young man who is studying for the ministry, and has pastoral duties in a South Sudanese congregation. It is representative of several narratives told to the researcher, and the segment describing the transformation in his belief system is shared in its entirety to best illustrate the strength that faith in God brings to informants' lives:

My life history is very important because I left my family in 1986. From 1986 until now I do not have my family. Because I ran away at 3 years, that's when the rebels came and attacked us. I ran away myself. Somebody took care of me. I do not know him because I was too young. I went to Ethiopia, living there for 4 years. I did not know the word of God. I did not know anything. OK, we met with the UN in this year. They saved us on the way until we reached Ethiopia. I am not thinking about the way I left my family. I am thinking about the way I could get my life. That is very important to me. If God gives me my life to keep, I will share that with Him later. Okay we run away again. The war broke; the bad war and we are still running again. We got to cross big, large rivers. I do not know how to swim. And that river, that is where I say, God still keeps me. I am not a swimmer. Before I ran away I would go to that river and I would pay someone to take me to the other side. It is the war then and I am not swimming anywhere. I tried to swim for it on that day and I got to the other side. Some people they died on the river. A lot or million of the people died on that river. And I am somehow alive. And that time, that is the time I came to be a believer. That is where I say God guided me a lot because I passed the river, where I do not know how to swim. I have heard this. Those who can swim they died, because if you go to the river and somebody jumps, they will put you down. And that time the old man jumped to catch me and that person died in the river. I had a bad life during that time. But it is not a bad life now because I can say that God cannot let me. God still gives me life until now.

Other positive outcomes of religious faith were noted by informants, including the hope that comes from belief in God.



People feel like according to Dinka tradition, they believe that religion is very helpful in terms of life or social being. They say religion is very helpful. It protects people and all these kind of things . . . Lots of people believe in God because they see God as the only protection that can protect life, and yeah, I think that's very, very important. There will be hope there . . . and people heard about histories of how God was helpful to some people that have been through that kind of sickness in some ways and all these kind of things. You know, it gave people hope and expectation of miracles, to get them out of that.

Several informants noted that their conservative Dinka values imbue their religious beliefs and practices. Examples that were given included honoring elders, viewing marriage as permanent, caring for children, avoiding divorce unless there are mitigating factors that could cause irreparable harm, and doing all that is possible to maintain life. One informant, who had originally planned to attend seminary and become an Episcopalian priest, has taken time off after graduating from college to reassess how his belief system fits with that of the Episcopal Church in America, which he described as less conservative than the Episcopal Church in Africa. This young man related that his beliefs reflect traditional Dinka values, which he felt were in conflict with some of those of the Episcopalian Church in America. He explained,

I only have problem with family values. I don't know the Bible that much, but I can defend my belief. I can defend my belief on the book of Genesis, Chapter 1, verse 28. You know, it says go and multiply. He said, be fruitful, go and multiply. So, as a Christian, if I did something that did not result in that . . . if people do not believe on that, on that particular verse, then I don't agree with that. You know, the Bible is very big, there are so many messages and people take the Bible according to whatever message that they like. But only that message from Genesis Chapter 1, Verse 28 is enough for me.

#### 4.8 Economic Factors

The majority of the LBLG, like many recently arrived refugee populations, are struggling financially. Informants were very open in discussing financial concerns, and

freely discussed their incomes and how they prioritize expenditures. All informants indicated that economic concerns weigh heavily on them. The economic realities of preparing for marriage and meeting kinship obligations have already been discussed. Other financial obligations mentioned included meeting daily living expenses, educational expenses, financial support for friends in need, medical expenses, and insurance coverage. A majority of informants described working in low paying jobs, often at or near minimal wage. Many are working two or more jobs, and may be attending college classes at the same time. A key informant explained how he attended community college and worked two jobs, each with a low salary. The two salaries allowed him to meet his needs and to send money home to family.

My job, the first job when I came here, was at [a local grocery store]. I started working at the grocery store as a baker at the food department for the whole year. Then I got promoted to be a cashier for 2 months and I was taking classes here in the community college; that was 2001. They paid me \$6.15. So it is above the minimum wage. I was okay. Then I got the job I'm still working on now, it is in a factory doing car parts. I got a job there for \$8.50 an hour and then I have classes here at the community college and the other job at the grocery store; so two jobs and classes.

Job responsibilities are often physically challenging, especially for those who are juggling two, or even three jobs. The researcher became aware of the long hours most of the LBLG worked when contacting potential informants to set up times for interviews. Interviews occurred at places of employment, at area colleges during breaks between classes, in churches on Sundays, and at informants' apartments during the waking hours between the completion of a night shift job and the start of a second shift job. Several informants spoke of negative ramifications which have resulted from working so many hours in physically demanding jobs.

If you get a job, like most of Sudanese here you get a very, you know like you don't get a kind of a job that you will have some rest or something, or do like a

very easy kind of job. So most of the jobs are kind of like, they are factory types of jobs and all these kind of things and thus make people work a lot of hours. You use a lot of energy. Some people can get two jobs and all this in order to get their financial needs covered. They work a lot of hours and that doesn't even give them enough time to sleep and to talk to people you know.

Another area of financial concern for the LBLG was the high cost of health care and the lack of affordable health care insurance. The majority of informants did not have health insurance. Several informants had moved to the Midwest from states they were originally resettled in so that they could find jobs which offered health insurance, and continue to live in a city with a LBLG community. Remaining uninsured was often a straight forward financial decision or the result of working multiple part time jobs that did not provide insurance coverage. One informant described what he and his friends have experienced:

Whenever you're thinking like okay, these months I have to pay this amount of rent, I have to send this to my brother, I have to pay this. I think it comes down to where they say okay, if I can't do this then I am going to do two jobs. And if they're doing two jobs, working two jobs and they cannot satisfy their needs they are going to think about doing three jobs. And that's quite hard for a person to do three jobs. And when it came that you are working three jobs and you cannot even pay your health care its more of a problem.

#### 4.9 Relationship between Economic Factors and Health and Well-being

All informants identified relationships between financial concerns and health and well-being. The most common concerns related to stress, depression, fatigue, and social isolation. One of the older informants shared that the divide between how one supports himself and his family in Sudan and how it is done here is very great. He explained some of the reasons why it is very difficult for people to cope with the poverty they are

currently experiencing in the United States. From his comments it is clear that the individual's self esteem may also be negatively affected:

Low finances really impacts health a lot amongst the Sudanese community here because it fuels depression among people. If you don't have access to getting what you want to make your life comfortable and all these kind of things, there is a big problem.

Working many hours, often on multiple shifts, contributes to sleep deprivation. Signs of sleep deprivation were evident during several interviews, when the eyes of informants appeared glazed, and speech was slower than usual. Many informants spoke of their fatigue. During one interview at a church, the minister interrupted briefly and asked to speak with the researcher. On returning to continue the interview less than five minutes later, the informant was found to be sound asleep in his chair. One informant shared a story related to sleep deprivation and health and well-being:

I heard of one boy that was involved in an accident. He did the accident because he was kind of like, he was sleeping. He was driving sleepy like this because he is working two full-time jobs in a factory and earning from job to job because he needs to pay dowries for his marriage. That complicates life, so that has cost him a lot you know . . . If you work a lot you don't even feel your body; if you work like two full-time jobs, you don't even feel your body. You know, you are always kind of unhealthy and all these kinds of things and you don't even have time to take care of yourself and do what is right. Like eating; you don't have the time. You only drive through eating at McDonalds.

Another informant described how working many hours can lead to social isolation.

The money issue, the financial instability, drives people crazy. They seem to be more anti-social when they're in that mood. So, all the family and relatives are trying to get them out of the mood because the more you work, more hours bring stress. And when you're stressed, you don't think, you don't socialize. Socialization is something that we have, we tend to socialize, we visit each other once now and then and when someone is busy enough that he or she can't see people then they're in trouble. This is where a lot of things come in the mind. You don't really tend to socialize with people again. So, you're deviated from the entire group and you become a lonely person. You don't want to talk to anybody but only deal with your own problems and I've seen that often.

The cycle of borrowing money at high interest rates, paying some back with loans from friends and eventually defaulting on loans, has been experienced among the LBLG. The consequences of rising debt are a concern in the community. Some are fearful that they will not be eligible for citizenship because they have been arrested for failure to pay debts. The impact of debt on one young man, and how he managed with the support of his brother and community to set a long term plan focused on education to resolve it, is shared here from the perspective of his younger brother:

My brother got married right after he got out of high school, worse decision ever. But I tried to roll with him because he was my elder and in my culture, there's no way he's going to listen to me. Elders are always up there. It's just like a hierarchy. I told him you know this is going to turn out differently than you thought because sometimes fantasy is not reality . . . He took this loan, got married, went back to Africa. I went with him of course, but I didn't borrow any money. I worked for my tickets because ticket costs nowadays are about two grand but, anyway, when he borrowed that money, he went home for 90 days. Guess what, the payment went up, he couldn't catch up with the bills. When he came back the car was not done being paid for because he borrowed money for the car and all of this all of a sudden collapsed. So, he is now worrying about how to pay money back and he worked in the factory, he worked two jobs. When he did that, he was going crazy. He was not paying attention to himself, health was unbelievable. He can't eat, he can't sleep, he was depressed. I pulled him over. I pulled him aside and said I think you need to go to school. Leave those debts, if you go to jail that's fine, but I'd rather you be in school than seeing you this way. You'd rather be in the school than seeing yourself strapped in a factory. So, I pulled him over. I gave him my place because when he came he couldn't pay for an apartment, so we were in one apartment with two friends. I gave him my bed and I slept on a couch for an entire year when he came. He did good, his grades were up and he keep up with his grade and he worked fulltime and that went fine. Now, I think it was a good decision to keep him in school than to see him working two jobs and not doing anything for his credit. So, I put him there. I know is a hardship place to be, being a student fulltime, sometime it's very hard and I think that was one of the reasons, I think, that make people give up their life because they know they are never going to get out of debt as soon as they think.

On arrival in the United States, the lost boys quickly found jobs, and many continue in the same job 8 years later. Arriving, as most of them did, with good English language skills, contributed to their success in finding and keeping jobs. Local

newspapers have carried stories that speak to their strong work ethic, and initially jobs were not difficult to secure. The economic situation in the Midwest has since declined. Manufacturing jobs have been particularly hard hit, and some of the LBLG are now dealing with unemployment for the first time. For those who do not have jobs, the picture is often grim. The researcher is close to a young man who has lost four or five jobs after being involved in fights with fellow employees. He has since moved to two different states, and has lost his job in each one. Drinking alcohol, a behavior that is not the cultural norm for unmarried men, is increasing with the stress of unemployment. Some of the lost boys have chosen to return to Sudan, where they are closer to their family, rather than stay in the U.S unable to work and contribute to the well-being of those who remain in Sudan. One of the community leaders among the LBLG had this to share:

Most of the time now, most of the boys who have no job, they are thinking, if I get a ticket now, I'm going back home, and stay there. Some boys they think, because he tried to get a job, he might be drinking, maybe drinking affects him a lot of the time, so he don't keep the job. So, sometimes they're frustrated and say, if I get a job now, if I get the money that can buy a ticket, I better go back home. Because here in America, I don't think I can get a bill paid for my rent, I have no car, so life is not easy. So I better go back home. So some of them, they just keep thinking about it. Because they say, I don't support my people back home, I don't support myself here, what can I do? I can't afford to go to school; those three are lost at the same time. So what can I do? So they are just thinking about back home, just be there, to let me see them there, struggle with them, that's another option that a lot of boys say, and say right now here.

#### 4.10 Educational Factors

Education was an integral part of the lives of the LBLGs before their arrival in the United States. Several informants spoke of a father, or uncle, or brother who had encouraged him or her from an early age to seek an education. Others had never thought of going to school until they arrived at a refugee camp where very basic schools were

available. Informants spoke with great passion about the virtues of education; describing the transformational effect it has in preparing them to achieve hopes and dreams so important to them and to the future of Sudan. An informant spoke to the meaning of education, and its ability to transform lives:

The meaning of education is changing lives. Like from where I was, I'm better. When I was in the village I had no future. My future was focused on the animals; like cows and goats, whatever. When I left home, my future changed from the animals to the education that I hoped for. If I go to school for this certain hours, I'll get a degree, I'll get a better job, I'll help my mom, my sister and my brother, and I'll help other people in the community. I'll be a leader of the people, who will call me, who respect me for what I have.

An additional incentive for seeking an education was to meet the expectations of elders, who advised the lost boys to take advantage of all opportunities for education as they were departing Kakuma for the United States. Several informants shared the words of Dr. John Garang, the former leader of the SPLA and Vice-President of Sudan at the time of his death, who spoke with them at the refugee camps. Several LBLG stated that his advice and expectations influenced them to focus on their education in the United States so that they would be better prepared to return and provide leadership in Sudan. A key informant shared his memories of when Dr. Garang visited the LBLG at the refugee camp:

Recently when this war came to Sudan, a lot of people that have education, those who are educated, they were the ones who came out on the top . . . So, that's how people see how important education is . . . When we left, we were told by John Garang, the rebel leader, he said, "Go to school, fight the future war of Sudan." He told us, this war of guns is going to end sometime, but the future war for Sudan is not going to end. Because the system that is in Sudan now is run by those who have education, and thus they are a very important part. You need to civilize and get education, and all these kind of things, and that's one of the reasons that people really feel why they need education. They say, "Oh, we need to go to school, and we need to get education done, so that we will help our people back home." I think we shouldn't feel like we'll go to school so that we will get a better job. No, but go to school so that we will help more people, to make change at home, and help people and everything there, that's why I'm here.

A much younger informant started his life in the United States living with a foster family and attended high school in the United States. Several years later, when he was the President of the African Student Organization at the community college where he was then studying, the researcher had the opportunity to hear him share this story about the meaning of education at a college wide leadership event:

I went to a movie theater, a cinema. And I went there with my host family, the foster family helping me. And it was during Christmas. And we went in. And we're seeing the movie called *The Polar Express*. And we've seen it at the IMAX where we sat down and we had the goggles. My little sister who is 8 years old and my other brother who is her twin, they were sitting one on each side. And then my other brother was sitting on the other side and mom and dad too. So we have the 3Ds that we were wearing when the movie started. And as we watched the movie, when the train comes, you really see the train, like it's really a train and it's coming into your vision. And it's like entering your eye. So I was kind of freaked out because I thought it was real. So I was kind of fighting with it. So I was using my hand thinking that it was really real. And I think with education in our community, it make things visible too. It makes things that you cannot see with a naked eye. Like if I had just seen that movie with my naked eye, it would be just a movie. But with 3Ds, it made me see that it was real. So you see, if you have education that is like the 3Ds that you're wearing. You will see your future. You will see how you can help your family. You will see what diseases are affecting your family. And if you have education, then you're going to use that education to be the 3Ds for the young ones coming so they can see their future too. And if we do that, I think it's going to build a stronger community, a stronger Sudanese community. And sooner or later, we might become like American. Not really like American. But a little bit up there. And I think it will minimize the number of people dying right now from simple diseases. Like for example my aunt who died from a disease called cholera, which might be simple here in America. But over there, you can't really help it. People die from malaria. Those are the simple things that can be cured if you have knowledge or education. But if you don't have that 3Ds called knowledge or education, you can't really do anything. So it's really, really important.

The female informants in the study shared a passion for education equal to that of their male peers. Although education was valued more for boys than girls when they were young in Sudan, these young women had the support of their families in Sudan to pursue higher education in the United States. They sounded no different from the male informants as they discussed their love of education, and their desire to succeed:



My family, they value education. Before my dad died in '96, he used to tell us, "Go to school. Go to school. Go to school." I don't know why, I just wanted it. Before even my dad had spoken a word about school or something like that; I just always wanted to be educated. I don't know why. But then, when we were in Kakuma, though – my parents were not there . . . so I was in Kakuma with my two little brothers, and with some of our relatives. And so, it's like, this is an opportunity and I really want it, and I know my father would have liked it too, for me to be educated. He will be so proud of that. Even though he's not there, his spirit is here.

#### 4.11 Relationship between Educational Factors and Health and Well-being

While it might be expected that outside pressure from elders expecting the LBLG to return with the education necessary to help with the rebuilding of South Sudan would contribute to stress and feelings of failure when educational goals were not met, very few informants spoke of negative consequences. One key informant did propose that the LBLG are not integrating into their American communities as well as other African immigrants because of their focus on returning to South Sudan:

People say, "I will go to school and go to Sudan and help my people" and all these kind of things. It's a lot of pressure. That's why you see Sudanese communities hardly to integrate with American population here, because of that dream or because of that kind of feeling. They feel like we need to accomplish this thing and go back home and do this and go back and visit, whereas in some other African communities, some people they feel like, "Oh, we need to stay here to make a living here, live here forever. But it's not like that for Sudanese; it's not like that at all.

Educational success brings a sense of positive self-worth and confidence, as is reflected in informant's responses in the previous section. Gaining the ability to take what was learned and integrating it with previous knowledge to find new meaning was found to bring about a transformation in self. An informant explained, "Bringing into your own learning something from outside and bringing it in to your own to change you, this is actually what I consider education. You are educating yourself. You are changing your

previous level.” Those who were successful and persevered with their studies felt they had gained respect in the community, and that they were able to contribute advice that was helpful to others. Having the knowledge necessary to make important decisions was identified as benefiting health and well-being. A key informant noted,

Education helps you to know how to deal with certain situations. Like when we talk about the health issues, if you are educated then you know what is the cause, you know what is the treatment, you know all the prevention, you know all of this and the fact that you are always capable of learning anything else, regardless of whether you are in school or not. It helps you because you are always in this culture because it is like your own culture now. Because you know that you are ready to learn from yourself and learn from others as well, and that is a good thing. It does not take you long to understand that something is against another person’s well-being and something is against your well-being, because you are right there to make a decision right away. You don’t make a decision based on one angle, you make your decision based on many angles, whereby you have already analyzed what situation will be best for your life, and that is a good thing about education. It helps you interact well and helps you understand well.

## 4.12 Political and Legal Factors

### 4.12.1 The Seed

The realities of war and politics have been a consistent feature of the lives of the LBLGs since their birth, and continue to shape their worldview today. A pivotal experience during their refuge in Ethiopia was a brief visit from Dr. John Garang, at that time the leader of the SPLA, and later the Vice President of Sudan. Informants described with reverence and awe the first time they heard Dr. Garang speak in 1988. He was described as a visionary leader who was viewed as a father figure by the LBLG. Many informants were able to recite much of the speech he gave. From their perspective the message shared was one of hope for the future, and his expectation that the lost boys would rise up and play a key role in providing the leadership necessary to secure the

future of a new Sudan. One key informant described his memory of that first meeting with Dr. Garang, when he was 8 years old:

When we were in Ethiopia, it was 1988, he [Dr. Garang] said, “You are the seed, and the seed will grow, and in 15 or 20 years from now, you will see that seed will grow, the world will see them. You are now in the desert, you are dying, but a few of the seed will live, will be alive, and the world will see them.” So when we were younger, the people call us the seed. In Arabic, they call that *tera*. Even when we came to the United States, people would still say we are the seed. And when we came here it is still now that the seeds are growing, that is what Dr. John was saying then.

This was the start of what several lost boys described as a personal relationship with Dr. Garang which endured as the LBLG traveled to Kakuma, and eventually on to the United States and other parts of the diaspora. He had high expectations for the lost boys, and they placed all of their trust in him. His vision was for the boys to work diligently in gaining the skills and education that would allow them to return to Sudan one day, and rebuild the country. Ultimately, this vision was shared by many others in the community. A key informant noted,

Every time that you see someone in the camp, then they really put more pressure on us, not to lose focus, but to keep focus, and to let us know that they are hoping for us to be the next generation who will move the country a long way, and in the right direction.

Informants credited Dr. Garang with bringing teachers to Pignudo and Kakuma, and ensuring that schools were established. They also credited him with negotiating with the U.N. and President George W. Bush for the refugee visas that allowed approximately 3,200 lost boys to move to the United States in 2000-2001. The idea of moving to the United States was not immediately welcomed by some of the boys, who initially feared it may have been a plot to harm them. For many, it was not until they heard from Dr. Garang himself that they agreed to undertake this move. A key informant described how this came about:

The U.N. came to us in Kakuma, and said that you guys will be allowed to go to America. And we said no because we assumed that might be President al-Bashir in Sudan; we thought that we might be sold away to America. So we refused. It took us a year that we would not do it. So when that happened, we invited Dr. John Garang to come to Kakuma. So the UN has allowed John to come to the camp. He came for 1 hour. And he said America is not like these African countries. It is a country of opportunity. It is an organized country. If you go over there, there are chances for you to be leaders of this country [Sudan]. So you just go. Go and do the best . . . So this is when we started coming.

Many young people in the LBLG community met with Dr. Garang again in 2004 at a national gathering of the LBLG in Phoenix, Arizona. The researcher had an opportunity to attend with several young men. Community elders and intellectuals from South Sudan and the United States were present, and many of them addressed the group. Dr. Garang arrived to speak on the final evening of the conference. He was attired in military uniform, as were the group who entered with him. The researcher was unable to understand Dinka, and the young men accompanying her were too excited to consider translating. At a later time they shared the themes of his speech, which once again focused on the need for the LBLG to continue to work hard at gaining the education that they need to be leaders. He also acknowledged that he would not always be here, and that there were future leaders present among them. A key informant shared what this visit meant to the community:

We were called from all of these states and we went, we went to see him. Even though you did not go and you were told that, he is here to see, he makes himself available whenever you need him and it is not always easy for most political leaders. When you need him he is there and he can come at a time you want help and that is how we describe him because he is always there through the journey with us . . . He has to come back and he always kept telling us do not rely on me, there will be many of me among you . . . then John said, I am preparing the way, but the one bigger than me is coming.

Dr. Garang was killed in 2005 when the helicopter he was traveling in crashed.

His death hit the LBLG community very hard. The loss experienced went beyond the loss

of a statesman, elder or soldier, to encompass the loss of hope itself. One informant described his personal response to Dr. Garang's death:

You know, back in 2005 when we lost our leader it was a tough trauma, a tough trauma, and actually let me tell you that is the only time that I have cried. I have lost many relatives but I know if something is going on, we can turn life around. But when we lost him, we were asking God to at least try to recover us from that illness. It was a great illness, a tough illness. Because he is a guy that has been there for many years and he understands everybody. It wasn't easy. We have been away from home for that long and that was because of our political impact, and when something went on at home it reached the point that he at least realized now we would be a part of the community. Every time we grow, we grow hoping that someday we will be back and be a part of that community and when something is again interrupting anything it is totally a tough situation and that can bring like going through a difficult time.

#### 4.12.2 Separation from Wives & Children

As discussed earlier, arranging a marriage is complex. The process involved in bringing wives and children to the United States is just as challenging, and often more frustrating. Informants spoke of the difficulties they are having convincing the INS that their marriages are legitimate, and have not been arranged in an effort to provide women an opportunity to enter the United States illegally. Traditional weddings in home villages, or in refugee camps, do not involve a government marriage certificate. An informant described returning to Kakuma refugee camp in 2004 to marry his wife, who he met when they were both growing up there. Four years later they had still not received final approval from the U.S. State Department which would allow her and their young son to join him here.

Sometimes they may need some things that I do not have. They may need the birth certificate of my wife. She was not born in a hospital. They say that if you do not have it, we still need it. What can I do? If I tell them that I do not have any way to get one, they say OK, then there is no way for us to bring her here. So, she will just be stuck there . . . Another one also, they say that we need a marriage certificate; they talk about a government marriage certificate. While what we usually have, it is a church marriage certificate. This is what we have in the

refugee camp because we were in a refugee camp and the marriage is not even in Sudan. They will say no. If you do not have a government marriage certificate we cannot do that. I had to pay money to the Kenyans so that I can get that. And that one will not be like a regular one that you can get from the government or from the real government. But if they want me to do it, okay I can try to do it.

Levels of frustration with the process of convincing the INS that their marriages are legal have been growing. It has reached a point where the LBLG are discussing gathering together as a group to go and speak with Senators and Congressmen in Washington, DC. Their hope is to convince the government that exemptions in the required documentation of marriage be made for those in a situation where such paperwork is not obtainable. A key informant discussed his concerns about the barriers that have to be overcome to get one's wife to the United States following marriage:

We were thinking there will be a day that we can go to Washington and talk about it. It is not happening right now because everybody thinks they are all busy, they don't have time anymore. It is a big, big, big issue now; it may get harder. My cousin, his wife is supposed to be here, but got a rejection letter. So, he is thinking now he has to go back.

Young men shared that they have had to bribe Kenyan officials before they were provided with documentation that may be acceptable to the State Department. In the meantime, they are fearful for the safety of their wives and children, noting that Kakuma is not a safe place to live.

#### 4.12.3 Interactions with the U.S. Legal System

Interactions with the judicial system and local law enforcement occur more frequently than the LBLG community would like. Disputes leading to contact with the police were discussed quite openly, and often a great deal of frustration was evident in the sharing of experiences. None of the informants shared a situation where they themselves were arrested or detained, but the majority noted situations where friends or

family were required to keep court appointments, make an appearance at the police station, or spend time in prison. While some of their frustration was directed towards the police and the U.S. legal system in general, several expressed that deep shame is felt by family, friends and the community as a whole when peers are imprisoned. The researcher approached a local South Sudanese religious leader, and asked if he thought one of the LBLG who has had trouble with the law would be willing to be interviewed so that the relationship between health and well-being and the behaviors that led to imprisonment could be explored. The religious leader replied that it might be possible if he were to ask some individuals himself, and also be present at the interview. Despite the support of this well respected community gatekeeper, no one who had been arrested was willing to be interviewed. Discussing behavior considered shameful with someone outside the community may well have been a factor in declining to discuss personal experiences.

Interactions with the legal system that were shared with the researcher included having multiple unpaid parking tickets, driving while under the influence of alcohol, car accidents involving fatalities, involvement in fights, dealings with child protective services, and interviews with the friend of the court in marriage and child custody disputes. There is a concern within the LBLG community that a lack of understanding of U.S. laws and how the legal system works is contributing to many of the arrests. Community leaders have invited the local police to meetings of the South Sudanese community to explain laws and when it is appropriate and necessary to call the police. An informant who participated in one such meeting described the rationale for inviting the police to speak to the group and how the community as a whole provides support to those who have been involved in criminal activity.

Sometimes we go to the churches. Sometimes we call our community; to call all the generation of the kids and young people to come around to have a meeting. Some are getting into trouble. They go to the jail. Some are drunk. We need to convince them. That is why we bring the people together. Some are listening and some are not. Like those who go to the jail for three times. The community struggles to get them out. We raise some money, because they charge them like \$1,500 in the jail. We need to talk to the community. Hey this person has worked in jail for around 3 months or 1 month or 1 week. We need to get him out, we come and we would put it in the meeting. Some people are counselors. They go and they counsel that person, so maybe that person will change and get a better job.

Not all interaction with the police was viewed in such a positive light. Several informants spoke of calling the police to protect people from harming themselves or one another. The results were not always those that had been anticipated. Informants spoke of police lacking knowledge of the South Sudanese culture, which resulted in their taking action considered inappropriate within the community. One informant expressed the anger he felt when he called the police to help prevent a fight from escalating. Instead of supporting the informant, who was trying to convince those involved to step away and stop fighting, he felt the police jumped in hastily and made matters worse:

You know, every time the police come they do not care whether you are Sudanese. As long as you live in America you will be held accountable according to American law. And that actually creates a big problem for us. Some of the others are not aware about many of the laws in America. So when you are trying to convince someone, the police will jump in and take things out of your hands. And now you have less prevention to do because the police are there. The police will say it is my duty, I got to do it. And when the policemen do it, they will not do it exactly right because they are lacking the culture as well. And sometimes that will make a very, very risky situation and that is very tough. And once you got this record, it will be always be held against them, regardless of what you can say, and that is not easy.

#### 4.12.4 Calling 911

A phenomenon of great concern within the LBLG community is the use of threats to dial 911 in order to influence situations that have traditionally been resolved within the



community. Informants spoke of situations where younger brothers or cousins were exhibiting behaviors they considered unacceptable. When confronted by their elders, they threatened to dial 911 and report that the older brother or cousin was harming them. A key informant described one such situation:

I have a cousin, he was drinking and I could not control him. I have a cousin from my mom's side and I asked him, "What are you doing here"? It is actually not good; I can't do anything because he will call on me to the police. That is pretty much what a lot of Sudanese use, and that is a tough thing to face right now. A lot of people get away through police. When you say something, they will say I am insulted and I am doing like this. They will make the police enter your records . . . and you have a bad thing with the police with that interaction and that is tough to deal with.

Informants reported similar situations with women who have called 911 to report that their husbands are beating them. Several informants indicated that the lost boys are aware that it is illegal to beat a woman in the United States, and that wives are calling 911 when they haven't actually been hit. Several shared that the women will then be provided with an apartment of their own, where they will live with any children the couple may have, and receive child support. Informants identified this problem within marriages as a lack of problem solving skills, caused in large part by cultural conflict which is resulting in shifts in gender roles. A key informant described his perspective of this crisis within the community:

There are a lot of propagandas around us. Like, okay, I came with my wife and maybe his wife came afterwards and my wife knows a lot about this, all the rights for the women. She will talk with the other person's wife and try to tell her what is going on. If there are some problems, hey, wake up, that's not how things are here, do this [call 911] and you have rights in the entire city, and then this marriage is now collapsed.

The enormity of this shift in gender roles became clear when the researcher attended the wedding of one of the key informants. The bride's elder brother and uncle were flown from Egypt, where they currently live, to attend the wedding. The uncle was

clearly the guest of honor at the wedding, and delivered the first speech at the reception following the ceremony. The hall was hushed as he spoke in Dinka. About 10 minutes into his speech, the researcher, who does not understand Dinka, heard him mention 911. It was repeated again and again. Everyone was listening attentively. A young man known to the researcher translated. The uncle was an elder who was very well known and respected throughout the South Sudanese diaspora. He was speaking not only to the bride but to all who were present at the reception. Although he had just arrived in the United States for the wedding, the elder was aware of the practice of calling 911 during times of dispute. He said that this practice must stop. Instead of calling 911, couples must learn to resolve problems. They must accept their responsibilities to their spouses. They must raise their children as Dinka. Problems must be solved within the community. Calling 911 was not an option.

#### 4.13 Technological Factors

It was surprising to the researcher that technology was rarely mentioned by participants unless it was in response to a direct question about its influence on their way of life or health. It is simply considered a normal part of life, just as it is to young native born Americans of the same age. From the time of their arrival in the United States, the LBLG used the phone to maintain contact with friends and family both in the United States and abroad. As a volunteer working with a group of four newly resettled lost boys in 2001, the researcher became aware of the amount of phoning that occurred soon after their arrival when reviewing bills received with the young men. Their initial phone bill was higher than the monthly rent. It did not take long before the word spread that a cell

phone with a national calling plan could be much cheaper, as well as a more convenient tool for staying in touch.

All of the LBLGs interviewed in their home by the researcher had at least one computer in the home. Laptops are used frequently, particularly by students. Cameras and video recorders are visible at community events, and serve as a communication tool with family and friends who remain in Africa. One informant purchased a camcorder, which was delivered to his brother by a friend who was traveling to Kenya. The brother collected the camcorder in Kenya, returned with it to Sudan, and recorded the ceremony when the informant's family and his prospective bride's family met to negotiate the marriage contract. The families were also able to view the informant and his friends. At the time the researcher met with the informant, he was eagerly awaiting the arrival of the tape so that he could see the ceremony and everyone involved, especially his prospective bride.

Technology was referred to frequently during discussions about health care. Limited technology was available in refugee camps, and it was nonexistent in much of rural Sudan. Several informants noted that one of the problems contributing to disparities in health care in South Sudan is that the North has all of the technology and facilities, while the South has almost none. They voiced their frustration that even the most basic technology, such as that needed to drill wells for clean water, is lacking in their home villages. Instead of counting on technological advances in health care, people rely on the skills of traditional healers. An informant explained his memory of health care in his village:

When we were in our home, we don't have all these technology and that kind of stuff. If you get sick people may try to do it traditional like coming and praying

and killing some cow or some people may go and look for some herbal medicine. That is what we do, because we live in the rural area.

While traditional healers are valued for their skill and ability to heal, many informants shared their concern that people are dying needlessly because they lack the technological infrastructure necessary to build and supply hospitals. Several local and national LBLG organizations are fundraising to provide funding to communities in South Sudan to build hospitals, and sending supplies such as operating and x-ray equipment.

Technology used in American health care was described by several informants as having pros and cons. The use of technology in helping to diagnose a problem was frequently mentioned as a strength, while the high cost of technology was a con. One informant explained this:

I think it's easier if we have technology. Like the hospital that we're in, it's easier to get access or to do some stuff that we can't really do if we don't have technology . . . but also it's really costly to have technology. So I can say there are a lot of good things. But there are some bad things to technology. Because I think with technology here in America, it's like going up like almost every year. And as the technology go up, the cost of it is going up too.

#### 4.14 Meaning of Health and Well-being

The concepts of *health* and *well-being* are so intertwined that they must be examined together. Each concept is interdependent with the other, creating a shifting whole which maintains the balance necessary for the productive life that was described as ideal. The majority of informants considered health and well-being to be one and the same. While all informants were able to provide a Dinka word for *health*, few were able to identify a Dinka word for *well-being*. Despite this, the English word *well-being* was used by many informants, particularly those working in health care settings.

Four intertwined spheres of health emerged from the data. These spheres reflect physical, mental, spiritual and social health, although they were not labeled as such by informants. As will be seen, all four spheres are reflected in this definition of health offered by a key informant, “If you are feeling positive, and are responsible on a community level to those who you are living with, then you are healthy.”

Physical health was most often described as the absence of illness and symptoms of disease. Many informants noted a relationship between physical health and the environment in which they live. One informant explained that

To be healthy means that you stay without any disease, you know, you stay healthy all the time whereby you don’t have to worry about having malaria, diarrhea, or cold. So if you don’t have one of those, we know you are healthy, but if you do have one of these things something might be wrong within you and where you live.

Mental health was described as being able to think clearly and to cope with life’s circumstances. *Mental illness* was defined as being crazy or insane. The stigma it carries is so great that relatively minor emotional problems may be hidden, and not discussed outside a circle of very close friends. Even discussing emotional problems with friends can pose a risk. Informants noted repeatedly that as Dinka or Nuer, it is important to the LBLG that they remain strong, and display no obvious weakness that may reflect poorly on themselves or their family. A key informant associated mental health with the ability to think clearly, with no intrusive negative thoughts:

If you’re free in your mind, then you’re free, you’re healthy. That’s the free I’m talking about. But if you are not free in your mind whereby you’re having bad dreams and when you get up or at daytime, you’re doing things that people think you’re not really OK in your mind, then we consider that person as a sick person.

Another informant described some of the symptoms that may indicate a mental illness:

Somebody may be acting differently, you know, he may not be giving responses that you expect, or he may be, there is story that maybe should not make you

laugh, but you will laugh to stories that maybe not deserve laughing, that means there is something, in his mind. He is seeing different things, you know. Some people also may be saying, “Oh, I’ve seen maybe a snake, I’ve seen somebody coming to kill me.” If you are doing these things that mean there is something, there is problem maybe in your mind.

Several informants noted the importance of social health, which was described as being immersed in and meeting one’s responsibilities to family and community. A key informant spoke of the importance of this connection:

Like talking to people is very important too for human health. When you talk to people it helps you to change your mind and relax and all these kind of things but work has led you from everything . . . and I think that that’s really affected a lot of people here.

Another key informant, who works in health care, described how difficult it is to maintain social health while living in the United States:

Our own community is very social; it has a very high social than any other community. For instance here in America it does not matter whether you know your neighbor or not. You might know your neighbor just by name or the house, but in my community it is expected that that you will be like just brothers and sisters living in the same area with your neighbor. It is difficult because you are renting here, you are renting in this side of the city and the other person is renting there. Even if you are renting in the same complex it does not happen because you do not have time to see your neighbor, because by the time you will be home maybe your neighbor is gone and by the time you will be all at home, maybe at night to go to bed, no time. The social well-being is actually decreasing.

Several informants stressed that without health, it will be very difficult for them to meet their responsibilities to others. One key informant described a close relationship between social and mental health:

I do not know of a lot of cases, but there are a few, that seem to be isolated and seem to be like, seem to be less cared for by the community. So that gives people isolation and they do not want to talk with other people. It brings aggressiveness; they do not want to hear anything. They just want to be by yourself and do it, and you can not do as other people tell you. So it brings aggressiveness and some a little bit of mental illness.

The final sphere of health that emerged from the data was the spiritual sphere. The *spirit* was always identified as an intrinsic part of the person; something that comes from within rather than from without. Spiritual health brings strength and contributes to a sense of well-being. It provides meaning and direction. A spiritually healthy person is more likely to find what they are searching for. A key informant described the spirit as being “like the way you believe, the way you live your life . . . To me, your mind, your spirit, what lives inside you always directs your life.”

For some, the spirit was nurtured through religious practices, yet it was described as being separate from religion and as requiring nurturing from within. One informant felt it was very important that the researcher understand the difference between practicing a religion, and experiencing spiritual well-being and explained it this way:

I think, to me, spiritual belief, or spiritual life, it doesn't always mean being religious. You go to church all the time, you do this for the church, you do this for the people, for the community, but you might not have those spiritual beliefs inside of you . . . There's something big around, somewhere, that we don't see . . . You could be a Christian, and I'm not a Christian maybe, I don't believe in anything, but we might have the same heart, we might have the same spirit. We might do the same thing, we love and care for people – and all those things – and happiness. And so, it's just like the spirit is really attached to your well-being and your health, and you have this spiritual life being, your spirit is strong. Keep it going, keep it burning, and you will get what you want, and if you want to change the world, you will do it.

While descriptions of well-being offered by informants were diverse, the majority spoke to an aspect of self-worth. One key informant summed it up this way: “The well-being is how good or bad you feel about yourself. So, if I am having a good time, I will feel good about myself. If I'm having problems, I am going to feel bad about myself.” Indicators of well-being include maintaining all four spheres of health mentioned in the previous section. Informants identified feeling secure, maintaining a sense of purpose, making progress towards the achievement of life goals, experiencing happiness, being

free, and earning the respect of family and community when referencing well-being. One young man spoke to many of these points:

Well-being might be concerned with the life, the way you are living, the good environment; physical environment and spiritual environment. You feel secure most of the time. It might be you feel secure even if you don't have finances. But you are free or you are spiritually happy or whatever. So it depends on the secure life you have.

#### 4.15 Maintaining Health and Preventing Illness

The majority of informants were concerned with maintaining their health and preventing illness. Most have experienced poor health in the past, and many arrived in the United States with health problems. The following is a listing of the variety of practices which were identified by LBLG as being important in maintaining health and preventing illness. Many were concerned that they were not able to maintain all of these preventive practices because of a lack of resources, primarily time and health insurance.

##### 4.15.1 Scientific Knowledge

Several informants spoke about the health education they had received at Kakuma. It was described as basic, but important, because it gave them the knowledge they needed to be healthy. For most, it was their first introduction to using scientific knowledge as a means to staying healthy. One informant shared that he developed stomach and bowel problems soon after his arrival in the United States. His doctor diagnosed him as lactose intolerant, and gave him the knowledge he needed to manage his own condition. He shared,

This is the modern world whereby you know that if you eat certain foods, there will be consequences, maybe tomorrow. So if you know that, like me, I don't eat milk right now, because if like I take that, I'll have stomach problems.



Written and electronic resources were referenced for information about health, and noted by this informant:

What I'm doing now, like, is I'm trying to eat food that I read in the book that these are the foods that you need to eat. Like, to be healthy, you must be eating some foods that have high fiber, drinking milk, and eating some fruits. That is what I'm trying to do now.

#### 4.15.2 Maintaining Cleanliness

Every informant pointed out a relationship between cleanliness and health, and shared that this was emphasized in the refugee camps. It was evident maintaining a clean environment was a near universal practice in the LBLG community as informants were interviewed in their apartments. The communal areas of every apartment visited were clean and tidy, and refreshments were always served on clean dishes and cups. An informant shared his understanding of cleanliness and health:

I know it is important to take shower, so that keeps my skin healthy, it removes germs. I know it is important to brush my teeth. I know it is important to clean my clothes. I know it is important also to clean maybe my utensils that I use, cut my fingernails, something to do with the cleanness of the body, cleanness of my environment, also is good for my health.

#### 4.15.3 Storing and Cooking Food Safely

Factors related to food safety and storage were mentioned by several informants. These included washing fruits and vegetables before eating to avoid illness, and storing food at the proper temperature. Informants noted they had no concerns about food storage at Kakuma. Food was in such short supply that it was eaten immediately when available. Several shared that after early mistakes they learned quickly and became much more cautious with food storage and preparation:

There's a lot of things that are bad, like buying meat that is almost to get expired, and you are not going to cook it in like almost a week. And that thing happened to me before, in America, because we buy meat and nobody cooked it. In the

meantime it was there until it went bad. So, let's say if we cook that food, and we eat it, we might not get a disease, but, who knows? Nobody knows.

#### 4.15.4 Eating a Balanced Diet

All informants spoke of the importance of eating a balanced diet and provided a basic description of the variety of foods they believe are needed to maintain health and prevent illness. They spoke of the importance of including proteins, minerals, vitamins, carbohydrates, and some fats, and were able to give examples of each. A key informant told the researcher that the LBLG learned much of this information while still at Kakuma, which may explain why there was minimal variation in the description of healthy foods.

One informant displayed a particularly high level of nutritional knowledge:

You know there are different types of food, and they do different things in the body. If I always eat, even like meat, I even lost my appetite, so the body even will be losing certain things, so I have to make sure my meal is consisting of different things. Like vegetables in my diet specialize in things like minerals and vitamins. I know if I need energy I should add things like bread and other cereals to my diet. I may need things like maybe milk or meat or beans, that will make a difference, because, all of them they contain different things. Some even help the body, like, those that have fibers, they are healthy. There are times that I know, like, when you eat bread, sometimes you even feel like, you can stay some days without going to the bathroom, so unless you eat those things that also have fibers, it will help you. So, eating is not just eating. You should know what you are eating; you should know that you eat variety.

Informants also spoke of the benefits of eating three meals a day; however, when asked about their eating patterns, it became evident that this was not the norm. A key informant provided rationale for eating only one or two daily meals:

Sometimes, I myself, eat once a day, and that will affect my health. Sometimes I spend the whole day without eating, and this will affect my health . . . When I came to Kenya, because of the shortage of the food, we have to eat only once a day. That means you have only to eat at 9:00 pm, at the end of the day. So, this was the pattern that we, that I have been accustomed to.

#### 4.15.5 Exercising

All informants reported that exercise is important in maintaining health. The researcher's field notes make frequent mention of observing pick-up games of basketball and soccer in the months immediately following the arrival of the LBLG in the United States. Several informants spoke of being influenced by countryman Manute Bol, who had a successful ten year career in the NBA.

While exercise is valued, most informants say there is not enough time for it now. One informant did fit in some exercise as a college student. "Sometimes I go to the gym at the school and then I lift weights, sometimes I walk, play soccer, and some different activities." Another informant noted that in some ways he gets less exercise now than he did in Africa, even though he is making an effort to exercise here:

You need to make sure you keep exercising to just keep you up in shape . . . if you take me back to Sudan now, I probably wouldn't be walking like them because I get used to like driving cars, sitting in a car all the time. Though I seem like I walk, I don't really walk if you put me down with them.

#### 4.15.6 Protecting the Community from STIs

Two male informants acknowledged that they were able to discuss sexually transmitted infections with the female researcher only because she was a nurse of their mother's age. These informants believe that to prevent transmission of STIs it is important to allow talk about sexuality, even though this is a cultural taboo. One informant shared that

In Dinka, it's really very hard to talk about sexual; you can't talk about it at all. But there is no way, it's like what I said before, either you choose to talk about sex, or either you choose to die. You have to choose which one you can do. It is better to talk about sex, and live, rather than to just leave it alone, and not talk about sex and die.

#### 4.15.7 Abstaining from Alcohol and Smoking

All informants reported that they do not use alcohol or cigarettes because they are bad for health. A key informant spoke of a relationship between alcohol and health:

I don't drink. It's not because I hate to drink, but I never try. And also I don't like the taste. Sometimes if you get addicted to alcohol it's bad for your health as well. It can just break some of your arteries or whatever in your lungs, so I don't do that.

While all informants were adamant that they avoid these practices, many expressed concern for lost boys who are drinking alcohol and smoking. The increasing use of alcohol, particularly among the “minors,” was noted as a growing concern within the community.

There was consensus among informants that smoking is bad for your health, even as they acknowledged that it was a common practice among adult men in their culture.

Several informants like this one pointed out a relationship between smoking and health:

I don't like it, but I know it is bad for my health, so if I just don't take it. Now I have experience from many friends who smoke, you know, sometimes they cough and they'll have heart problems sometimes, so I don't smoke because it's not good for my health, you know, it might affect my lungs.

#### 4.15.8 Socializing

The importance of socializing with friends came up again and again in relation to maintaining health and well-being. Spending time together, laughing, sharing stories and jokes were all mentioned as means to forgetting worries and stress, at least temporarily.

One informant stated that

I don't know how people think about it, but for me I feel like even, you know, like having people around you, like talking to people, socializing with people, and all these kinds of thing, is very important too. I think it doesn't make your body stay healthy but I think it makes your mind stay healthy.

#### 4.15.9 Maintaining a Positive Attitude

A positive attitude was frequently correlated with positive outcomes, including a means to survival. As discussed earlier, it contributes to health and well-being, and decreases the likelihood of mental illness. A young man explained the role of a positive attitude in may contribute to a cure:

If you believe in the medication that you take, you will be all right. This is how I believe it. It's more about the mind; what you think about it . . . I know, my belief, that saying I'm not going to get into any sickness and its seriousness keeps me from being sick too.

#### 4.15.10 Avoiding Environmental Hazards

Exposure to extremes of temperature is considered bad for health. Other environmental safety risks mentioned included walking in hot weather, handling sharp objects, and lacking awareness of unsafe situations. One informant emphasized the importance of assessing that any environment he entered is safe:

If you are in the field and you are playing in a not certain environment, that could harm somebody. You only play in a good environment and you make sure that the scene is safe in order for you to do any kind of activity. You need to observe the scene before you do anything, like if you are playing in the playground

#### 4.15.11 Avoiding Infection

Many of the informants described the importance of protecting oneself from infection or illness by avoiding close contact with people who are sick. While they described an obligation to be present with close friends or family who are sick, if the relationship is not close, sick people should be avoided until they are well again. Several informants noted that an increased risk of catching an infection was linked to living in overcrowded conditions. One explained that

Overcrowding is a problem too. Because they stay in a small place maybe, if one person get sick that can cause all of those around him, and there are ways to

prevent it . . . Like this room now, it is very small, and if we were four people, or three people in here, that would be too much. If one person get cold maybe, or cough, that would be a problem, so we can all get it.

#### 4.15.12 Getting Enough Sleep

Sleep is considered crucial for health and safety, yet most informants note that they survive on very little sleep since time constraints keep it low on their priority list.

One informant defined enough sleep as “the most you can get.” Reports of sleep deprivation were common. One informant shared an example:

To maintain health I think like you need to get enough of sleep . . . I heard of one boy that was involved in an accident and he did the accident because he was kind of like he was sleeping—kind of like sleepy, driving sleepy like this because he is working two full-time jobs in a factory and earning from job to job because he needs to pay dowries for his marriage and that complicates life so that has cost him a lot.

#### 4.15.13 Praying to God

When asked how they came to be in America, LBLG invariable credit God. The majority of informants shared at least one experience of surviving a dangerous situation through the grace of God. An informant described his belief of the link between health and God:

Health does have a connection with religion. If you pray, the God gives you something. Maybe sometimes, like back then when I was back in Sudan, like we don't have water. So you drink bad water. But you ask God to protect you while you're drinking water. So if anything happen to one of us, we only pray.

#### 4.15.14 Relaxing

Informants addressed their need to relax, especially when they begin to feel stressed. Relaxing was described as necessary to free the mind, and keep it healthy.

Socializing, mentioned earlier, may lead to relaxation. Some other examples of relaxing

activities were running, reading, telling stories, joking, playing games, and napping. A young informant spoke of the health benefits of napping:

If you were working hard, had a long day at work maybe, if you come back sometime, you get your body a rest. You sleep, get sleep, if you have headache, you have to take a nap for mental, take shower, take a nap that will let your brain cool down and later on you'll be healthy.

Another informant spoke of her favorite way to relax:

I know that exercising is good. You try to exercise your mind. It doesn't always mean when you go out there running, or go to the gym. It's not all about your body. It's about this relaxation. It comes to me. I always like that. What I do most often is just read. That's my favorite thing. I just pick a novel, and read. When I read a good novel, I feel like I am in the air. It's just like, "Okay." So, that's one thing. I read to relax my mind.

#### 4.15.14 Seeking Advice

Several informants described how they sought advice from American peers or the families that sponsored them following arrival in the U.S about healthy living practices. A young informant attending college described the health practices he learned from his basketball coach, who told the team that they would play better if they cut back on pop, didn't smoke or drink alcohol, ate plenty of carbohydrates and got a good night's sleep before the game. Another informant described his practice of observation followed by questions:

I think being here and seeing people, how they do things and how they're trying to keep up to be healthy; you can ask them like, "Why are you doing that"? And if they tell you why they're doing that, then you want to try it too. It's like being at the gym and somebody is doing lifting and you didn't know how to do that before. So if you try and you don't do it right, then like, "How did you do this before? Can you show me again?" . . . We have to ask them also, what kind of things do people practice? Do they run a lot just to keep healthy? Or the people who sit in a car like us driving all the time, what do they do to keep healthy? So I think that has impact on me as a person coming from another country. And like I said if you're in Rome, behave as Rome do. So if we're in America, then we have to behave like them. How do they stay healthy? So stuff that they do to stay healthy, we also practice them to stay healthy.

#### 4.16 Health-seeking Behaviors

If an illness was not considered serious, informants spoke of treating themselves with over the counter medications. Friends were consulted for advice; particularly if over the counter medications were not resolving symptoms. Seeking care from a physician was considered a viable option only for those who carried health insurance and had a good relationship with a physician. If desperately ill a friend would provide transport to the emergency room, or dial 911 for an ambulance. Variables noted that influenced decisions about when to seek care included the nature and severity of the illness, access to health insurance, the potential for shame attached to the illness, and whether the illness was severe enough to prevent LBLG from working or attending classes.

Self medicating was described as the norm for non-emergent illnesses by the majority of informants. A key informant described what he sees most frequently in the community:

Sometimes people go to doctors, but sometimes they ignore it. If they feel like having headache, you go only to shop and get Tylenol or whatever you are supposed to get and start taking it and forget going to the doctor. Sometimes if you need like, some brofin, and you feel like taking that, you ask your friend, "Can I get some brofin? I have headache." And instead of going and finding out what was the cause of the headache, it is still there. So most of the time they don't go to the doctor as is required. Talk of somebody like me; I took almost a year now without going to a doctor.

All of the informants said they turn to friends when seriously ill. Friends listen, offer advice, and provide support. One informant spoke of the importance of including friends in the decision making process when ill:

You know, it is good to tell out what you are suffering for . . . I will involve those who are my friends if I'm hurting or just feeling not OK, or ill, or depressed. I can contact any of them, tell them how you feel, and they will give you advice. They will because, they say, one hand can't clap. That would be our tradition, to wait, if it is a headache, maybe even for 1 or 2 days. If it is something hard, and I didn't



like that thing, or it was really hard for me, they can even advise me to go and see a doctor if it is something that needs a doctor.

If a friend is concerned about an individual who he believes to be very ill and unwilling to seek health care, the friend may take that individual to a doctor or emergency room himself.

Several informants described seeking advice from American friends when making decisions about seeking health care, particularly those who sponsored them upon arrival in the United States. A key informant described the role his sponsors have in advising him when he is ill:

There are some of the families that we feel are like our real people, because they're always concerned whenever we have those problems. Like if I have the problem, I can tell anyone of them that I'm not feeling good, I'm like sad, and I may talk to my family doctor or I can even tell one of them to go and talk to my family doctor.

While many informants spoke of the benefits of seeking care from a physician at the first sign of illness, doing so was not the norm. One key informant, who had a physician and health insurance, did speak of the benefits to from seeing a health care provider at the first sign of illness:

In people, it is better to seek healthcare as early as possible, because if you might wait, until it becomes very tough, it might cause a lot of time, a lot of money and everything, and even it will lead into tough treatment. So, it's better to go, to seek care earlier, when the thing begins.

The decision to seek health care is seldom reached until an individual is too ill to work or attend classes. A key informant with a degree in a health related field described the normal health seeking pattern he witnessed within the LBLG community:

When everything really, really becomes serious, because we Sudanese or African, we say that we're changed but we're not really changed because we still be like, okay if I feel headache or fever, I still go to work and say, "This is not a disease." And then I go and work there, and work there until I feel exhausted. Then I come home and then I go to bed after I take a shower, I go to bed and then I sleep there.

When I feel like I'm okay, then I still come to work. And here, when it becomes really, really serious, then I need to go and see my doctor. If the doctor say, "Okay you will be off for a certain period," that is when I will be off. But if the doctor didn't say that, even if I feel really, really serious, then I still come to work.

While a person experiencing symptoms of mental illness is considered to be unhealthy, all informants agreed that even if he is aware of the seriousness of his illness he will not seek treatment because of the shame. This shame reflects not only on the individual, but on his family as well. Mental illness brings bad family credits, and limits future opportunities for marriage. Peers or family may recognize changes in behavior that alert them to the problem. While there is concern that others outside the close circle of friends may learn of the person's illness, there is also concern for the safety and well-being of the person involved. In most circumstances, it is not until friends become concerned about their own safety or the safety of the individual experiencing mental illness, or no longer feel they have the ability or the resources to help the individual, that help is sought from the health care community. An informant explained how friends may intervene in seeking health care for someone with very serious symptoms:

If it is a kind of serious mental disease, that's where people can advise him or her to go to see the doctor, or if he is not willing to go, some people can volunteer and take him to the doctor, and if he is not talking too, like, some people will be that serious mental problem they don't know the word to say, so, somebody can go and say something about that guy, how he feel or how he act to the doctor.

#### 4.17 Barriers to Care

Several barriers to health care were identified by informants. These included lack of health insurance, lack of trust, gender roles, stigma attached to certain illnesses, limited time, shame, and loss of hope.

#### 4.17.1 Lack of Health Insurance

The primary barrier to health care which was identified by every informant was the lack of health insurance. While the majority of informants hold at least one job, sometimes two or three, many jobs are part time or temporary positions that do not provide health insurance. Even when health insurance is available, the cost of the required contributions, deductibles and co-pays may be so great that informants declined coverage. A key informant described the effect this has on seeking care:

Right now, I have friends who don't have Medicaid. They don't have insurance. And whenever they're sick they just stay at home because they know when they visit the hospital the bill will come right up after them. So a lot of people are scared to go to a hospital because they will not be able to come up with the money . . . So a lot of us, even myself, I spent almost 4 years, right after I left Bethany, I had no medical insurance. But I thank God that I have good health and nothing happened to me.

Many informants described personal experiences when the circumstances were so severe that they felt there was no alternative but to seek health care from a doctor or hospital. The consequences of the resultant debt were such that many described being forced to drop out of school, work two or three jobs, postpone marriages, and decrease or stop remittances sent to support family at home. Several informants shared the same story of a friend which illustrates the level of fear experienced when health insurance is lacking:

One time, the guy was riding his bike. And it got hit by a car. And then he was put in the ambulance. And when he was in there, he was feeling better. So he got up and was like "Where am I, why am I in here?" They were like, "We're taking you to the hospital because the car knocked you down." He jumped out and ran. The reason is because there's no health insurance. And what is coming, is bill. And we don't have that chunk of money to give the hospital. And that thing is affecting a lot of people, which is bad. I can say 90% of the people, of the lost boys, don't have health insurance. And it's really bad.

Another young man shared an even more frightening scenario that may occur because of high costs and no insurance:

Like, if that lady or a girl is pregnant and you know, back home you can give a birth on your own, but over here sometimes, it is too complicated. If you have a Medicaid or like insurance, you can deliver in the hospital. But, in Africa, there are midwives, people traditionally that can help you doing that. But, somebody may think that, well, I used to do that one in Africa, so let me force myself to do it by my own. Its not 100% perfect, you know. Something will occur like there's a chance you can not support yourself in that process. If you are with somebody in hospital they know what to do to take care of you.

#### 4.17.2 Lack of Trust

Establishing a trusting relationship with a health care provider is considered important. If trust is lacking, LBLGs shared they will be concerned about confidentiality, and are unlikely to share information that is considered personal. A key informant who serves as a medical interpreter stressed that lack of trust is a key barrier to care:

Sudanese are very open to the health professional that they know because it's a lot easier for the Sudanese to open up when they know somebody. So let's say, you come to me and you say, "Emmanuel, I see you've got a problem." So it will be a lot easier for me to talk to you because I know you. Let's say another nurse comes in and tries to talk to me. I will never open up. I don't know them and I don't know whether they will go and keep that with confidentiality what they're trying to tell me or not, because I don't know where they live. I don't know what they're going to do with that information, so the best I can do is to limit myself or how I can talk to that person.

#### 4.17.3 Gender Roles

Traditional gender roles prohibit women and men from openly discussing concerns related to sexual and GI/GU function, particularly with those of the opposite gender. There is a strong preference for same gender health care providers, with many informants noting that women will refuse to have a male health care provider. Male informants preferred a male health care provider, although one informant noted that this is beginning to change as they adapt to the culture here. A key informant emphasized how communication can be negatively affected in such situations:

Something I observed back in Kakuma, and even now I feel it in me, and some other Sudanese feel it, people pretend not to deal with things that are not supposed to be. Like, they talk of when a boy from Sudan went to the doctor and by that time he found the doctor is a male. He will explain everything to him, without fear. But sometime it comes that he finds the doctor is a lady; there is a tendency of fearing, of not telling the truth. That is what I observe.

The need for privacy across gender includes interactions with interpreters. Several male informants worked as interpreters and spoke to the difficulties that arose when interpreting for a woman:

And so in my traditional people we are keeping privacy, to the doctors, to the nurses. And that most of the time also it happen with our ladies, even here. If you see a Sudanese lady which is sick now and take her to a doctor, take her to a hospital, and you call me and say “Atem, can you translate for her, what she say, what she’s feeling to me?” she will not tell me what is the right thing. She will just tell me something that’s not even right. And when you write a prescription, it will not be the right prescription to her, because of the privacy with which she was grown up, the life of privacy that she has here. So it is very difficult to identify the diseases from Sudanese women.

#### 4.17.4 Stigma

The stigma associated with certain diseases was identified by informants as a significant barrier to care. The diseases mentioned most consistently were sexually transmitted infections (STI) and mental illness. If a treatment is sought for a potential STI, it is unlikely that the individual will verbalize the concern directly with a health care provider. It may be approached in a round about way, and requires an astute listener to recognize the concern. One informant told the researcher,

People pretend not to talk about it. For example, when a person is having STIs, it is hard for him to tell the doctor that I am having this disease. Sometimes the men can come and tell them, “Can you take my blood, can you take my urine, because I don’t feel well.” And he can not tell them the reality at that point, so they tend not to talk about sex cases.

The stigma associated with mental illness prevents LBLGs from seeking treatment for less serious concerns. Informants noted that seeking counseling from a health care provider is considered unacceptable. One explained that

We Sudanese, especially the Lost Boys and Lost Girls, we don't acknowledge that we are mentally stressed. We are stressed. We are depressed. We don't really like that term and we don't even take time to internalize and say, "Oh, I have a problem and I'm mentally affected. I want to see a counselor." Those kinds of things, depression and stress, people tend to associate them with insanity. And you don't want to be categorized in that area. There's a stigma there in the way that people have been brought up, the way that we have been taught in the refugees' camp. So if you see a counselor, you have a mental problem. And even if you have a simple problem that you talk to a counselor, I will look into that stigma that I already know, that if I see a counselor people will know that I have a mental problem, even if I'm just stressed.

#### 4.17.5 Shame

Multiple informants described the difficulty some LBLG have in recognizing when they are unable to cope alone with life's circumstances. The causes can be many, but the outcome is often a sense of lost dignity and a feeling of shame so great that the individual isolates himself from the community. As a result of the isolation, peers may not be available to provide advice when there is a need to seek care. This can be frustrating to all involved.

It's too hard because you know, we grow up where we say there's nobody better than each other, there's nobody who is better than me. Like if you come to me and say "William, is there a way that I can help you?" I will say no, because I know that I am failed here, a lot of them are, and I don't want to admit it to you. And some of the boys they have that feeling, they are a failure, in part of the thing that they wanted to do. But they don't want to admit it to somebody or to talk about; they just keep it by themselves. And that's what happened.

Seeking care for any reason from a professional who provides counseling reflects poorly on an individual and possibly his extended family as well. Another key informant spoke about the harm that may result from such an encounter:

It is embarrassing as well to you as a young man, going to see a social worker here in this country and talk about this because in my community it will create something negatively towards your family and we care much about family credits. So you are spoiling your family credit, and try to handle it alone.

Coaxing the individual from isolation and encouraging community engagement are generic caring practices that support mental health. An informant described how this is accomplished:

So people when they are in depression, and then people come as a group. They felt that their fellow Sudanese care about them. Their fellow Sudanese think about them. Their fellow Sudanese are there for them. So they feel included. But when somebody has a problem, they feel isolated. When people come as a group, they feel included again, and then they become energetic and they can function again.

#### 4.17.6 Time Constraints

The LBLGs lives are as busy, if not busier, than most of their American born neighbors. With work, school, and family commitments, caring for oneself becomes a low priority. An informant explained this difficulty:

Some people feel like, “Oh, I am busy; I don’t have to make this appointment. I will make this appointment tomorrow, I will make it next day, I will make it next day,” until all of a sudden you are, like if you are sick it is serious.

Several LBLG shared that they are finding it difficult to provide the support and care that their friends need because they too have busy schedules. A key informant noted that “Yeah, that support is there in any Dinka community that you are living in. But here it is difficult, because anybody in America does not have time to deal with all of these personal issues.”

#### 4.17.7 Knowledge of Health Care System

Many informants noted that a lack of understanding of how or when to access the health care system is a significant barrier to care. One young man explained, “A lot of

people they are not really aware of the procedure that you do in order to reach a doctor. Like, make an appointment, be on time, or explain whatever you think that you have.”

#### 4.17.8 Loss of Hope

Faith in the power of medicine and the knowledge held by health care providers is so great that when no definitive diagnosis emerges after examination LBLG have spoken of their problem being so severe that they can not be helped. Several informants described their reluctance to seek further care because no one could identify what was wrong with them. A key informant explained how frightening an inconclusive diagnosis can be:

If they go to a hospital, their expectation is that, you know, it's America. They are the most powerful especially in terms of medicine and other things. So people went to the hospital and they are being given medicine, then they come back and they didn't see a change. Some of them are frustrated because they know this is the best place where they can get medicine. And if their disease still persists, they become worried that if something doesn't get cured here, then I'm in big trouble, or my problem is bigger than that.

#### 4.18 Traditional Healing Practices

The most striking aspect of informants' responses to questions about traditional healing practices was that knowledge of these practices has been lost to the LBLG in the United States. All of the informants said that they have no practical knowledge of traditional healing practices. Yet it was obvious from listening to informants that they respected the knowledge and skill held by the traditional healers in their villages and the refugee camps. One informant shared that in his village,

We have these particular people that are there to treat you when you feel unhealthy; when you are unhealthy you have to get somebody. For example, there are some people that when you are courted by malaria, he is the only person who



can go to the forest and get some different kind of leaves and give them to you. And after drinking that leaf, the feeling is that you will be fine.

Traditional medicines were used in the refugee camps, although treatment from a health care provider at the camp clinic or infirmary was the first choice. One key informant, speaking of his time at Kakuma, noted that traditional medicine could be effective when modern medicine was not:

Sometimes when I was there if I take the modern medicine and then I don't recover from that one, then I can maybe use some of the traditional medicine in order for me to recover. And some of the traditional medicine they work better compared to some modern medicine.

#### 4.19 Experiences with Professional Care

As discussed earlier, the majority of informants do not have a personal physician. While they all were covered by Medicaid insurance for the first several months after they arrived in the United States, most have lacked health insurance since then. Many informants' only experience with professional care was their initial assessment with public health nurses at the Health Department shortly after arriving in the United States. This experience was described as positive by the informants, with several noting that their vision and hearing improved as the result of referrals made to audiologists and optometrists. Many remembered the public health nurse following up with a visit to their home, which allowed them to talk further with someone they had already met in an environment that was comfortable for them.

Negative care experiences revolved around ignorance of cultural beliefs, lack of information, ineffective communication, and lack of respect. Several informants noted that difficulties have arisen with health care providers who do not understand their

culture. If cultural norms are violated, trust is lost. Informants indicated that it is easier for them to talk around a sensitive topic, rather than state it directly. When a health care provider asks direct questions about symptoms of illnesses that are taboo, including mental illness and STIs, the integrity of the individual is attacked. One key informant noted that

If doctors know that the Sudanese community has problems, a culture of mental problems, then they should find a way they can approach them. Not to let them feel that they have been violated. If their cultural wrong is being avoided; it makes them more comfortable . . . Sometimes some people lose trust. It depends on how somebody approaches you, you know.

Many informants described experiences when no medical diagnosis was established despite their providing the physician with a description of their symptoms. Frequently the dissatisfaction occurred when a physician was focusing on a physical cause for a problem the informants knew to be more than just physical. Symptoms that were mentioned often by informants included headaches, aching joints, and stomach pains. The informants' expectation was that the physician would recognize the meaning of these symptoms, and ask follow up questions that were culturally appropriate. Instead, they described doctors who did tests which did not identify the illness and then failed to explore further to find a cause. One informant explained:

I went to the doctor and said that I always get headaches. They tried to put like x-ray. And they say that we didn't find anything. And I say, "Then what is wrong with my head?" Here [touching back of head], I sometimes feel too much headache all the time. They said nothing is wrong.

When the researcher asked the informant what he thought caused the headaches, he replied, "Maybe thinking too much. Worried thinking about going to job, school, and your parents back in Sudan, what are you going to give to them? And getting married, how much money you're going to pay." For this informant, the physician demonstrated a

lack of caring and lost credibility through his inability to explore beyond the physical symptoms while preserving this informant's dignity. Another informant shared a personal experience in an emergency room which illustrated lack of caring and respect, and resulted in feelings of anger and powerlessness:

There was a time that it [pain] happened while one of my American brothers was there and he took it seriously and take me to hospital, to emergency room. It made me even feel weird because in came different doctors. They put me in their big machine and all these kind of things that made me uncomfortable. It took me 2 hours you know, waiting in line and going through all this problem and wait for that to come back. Finally I never even had a result about it. I didn't even take medicine and it was negative and I was not even told, or I was not even given feedback. You know, what I get was they ask, "Okay, what did you eat yesterday and what did you eat and what did you do for the whole day yesterday what did you do and where did you go?" And all these kind of things; and I feel like it wasn't related to that. I feel like that one will give them a bad assumption and they will say, "Oh, because you eat this type of food that's why you have this sickness." I went to hospital for those and finally I get medicine bill for about \$1,700 and I pay that one for the whole year. Yes, and they took control of it and they didn't even find the result, they didn't even come back and tell me exactly what was the result. What I get is bill and no concern and so you feel bad about it.

Fewer positive experiences of care were shared than negative experiences. The researcher gained first hand experience of the importance of accommodating traditional practices while accompanying a Dinka friend throughout her labor and the birth of her son. This woman's first child was born at Kakuma, and her second child in a U.S. hospital. She had a midwife and other women present at the first birth during which she squatted for the delivery. The delivery went well. She described her second delivery as very frightening. She knew very little English at that time, and a translator did not arrive until a short time before delivery. There were many people in the room, both men and women. She was attached to a fetal monitor which she was sure would hurt her baby. The monitor remained in place until the baby was born. She described being forced to deliver with her legs in stirrups. When she cried she was given an injection that gave her a

headache but did not take away the pain of giving birth. This friend was very frightened to return to the hospital to deliver her third child, so her husband asked the researcher to accompany her. He and his wife also made the unusual decision that he would be present in the birthing room. On admission, a female obstetrician and female resident were present for the delivery, along with two female nurses. The woman's husband was given a chair behind the curtain, where he was present but shielded from viewing the delivery. He only spoke twice, each time asking the researcher if his wife and baby were well. The nurses and obstetrician accommodated the mother's preferred birthing position by first showing her how she could use footrests and a bar for support while squatting on the bed. She was then asked whether she would prefer to deliver on the bed or to squat on a sterile drape on the floor. She chose the bed. The obstetrician suggested that it would be wise to do a baseline fetal monitoring, and if all was well it could be left off unless fetal heart tones dropped. The mother agreed to this, and the monitor was soon removed. She managed her pain through breathing. The nurses spoke quietly, provided encouragement, applied compresses, and gave backrubs. This couple was very pleased with the care they received.

#### 4.20 Presentation of Patterns and Themes

Phase three of data analysis focused on the discovery of patterns and meanings in context in regard to the domain of inquiry. Data from Phase one and categories from Phase two were scrutinized for recurrent patterns, with particular attention being paid to consistency of patterns and contextual analysis. Descriptors and categories in support of these patterns affirm the confirmability and credibility of the study and the meaning-in-

context of the findings. As informant responses that reflected the categories were discovered and rediscovered in repeated interviews, saturation was determined.

The six patterns which emerged from this phase of analysis are presented below.

1. A pattern of belief in a powerful, omnipresent God.

*Supporting categories and cultural context.* Kinship and social factors, economic factors, religious and spiritual factors, health seeking behaviors, experiences with professional care, cultural values and lifeways, environmental context, political and legal factors, barriers to care.

2. A pattern of living life sustained by hope.

*Supporting categories and cultural context.* Political and legal factors, religious and spiritual factors, environmental context, cultural values and lifeways, kinship and social factors, economic factors, educational factors, barriers to care, maintaining health and preventing illness, health seeking behaviors, meaning of well-being

3. A pattern of thinking too much.

*Supporting categories and cultural context.* Environmental context, political and legal factors, economic factors, cultural values and lifeways, kinship and social factors, educational factors, meaning of health and well-being, maintaining health and preventing illness, barriers to care, experiences with professional care, health seeking behaviors

4. A pattern of an emerging reality of disruption in social balance.

*Supporting categories and cultural context.* Environmental context, kinship and social factors, cultural values and lifeways, economic factors, political and legal factors, religious and spiritual values, maintaining health and preventing illness

5. A pattern of communal interdependence and care.

*Supporting categories and cultural context.* Kinship and social factors, cultural values and lifeways, economic factors, educational factors, political and legal factors, technological factors, meaning of health and well-being, maintaining health and preventing illness, health seeking behaviors

6. A pattern of honoring traditional human values.

*Supporting categories and cultural context.* Environmental context, kinship and social factors, cultural values and lifeways, religious and spiritual factors, economic factors, meaning of health and well-being, educational factors, political and legal factors, health seeking behaviors, barriers to care, experiences with professional care.

The three major themes derived from this study are presented below.

*Theme One: Spiritual care, grounded in a belief in the strength and wisdom of one God, is health promoting and illness preventing.* The patterns that supported this universal theme were (a) a pattern of belief in a powerful, omnipresent God; (b) a pattern of living life sustained by hope; and (c) a pattern of communal interdependence and care.

*Theme Two: Contributing to and meeting the expectations of the community are necessary for health and well-being.* The patterns that supported this universal theme were (a) a pattern of honoring traditional values, (b) a pattern of communal interdependence and care, (c) a pattern of living life sustained by hope, and (d) a pattern of thinking too much.

*Theme Three: The conflicting expectations of two cultures are affecting health and well-being.* The patterns that supported this universal theme were (a) a pattern of communal interdependence and care, (b) a pattern of honoring traditional values, (c) an emerging reality of disruption in social balance, and (d) a pattern of thinking too much.

#### 4.21 Summary

This chapter presented the findings from the second and third phases of data analysis and culminated in the presentation of three major themes. The second phase of analysis resulted in the identification of thirteen categories related to the domain of inquiry which is the culture care beliefs, meanings, and practices related to the health and well-being of South Sudanese LBLG refugees within the context of their new home in the midwestern United States. The third phase of data analysis resulted in the emergence of six patterns related to the domain of inquiry. The following chapter will present the fourth and final phase of data analysis which is the identification of the themes.

# Chapter 5

## Discussion of Findings

### 5.1 Introduction

The purpose of this ethnonursing study was to describe, analyze and interpret the culture care beliefs, meanings and practices related to health and well-being of South Sudanese LBLG refugees resettled in the United States. The specific goals of this study were to (a) utilize participant observation and semi-structured interviews to elicit emic data that will provide in-depth understanding of health beliefs and practices of South Sudanese LBLG refugees, (b) identify how worldview and cultural and social structure dimensions influence the LBLGs' generic and professional care beliefs and practices, (c) discover or describe culture care knowledge including traditional generic (folk) and professional caring practices that promote the health and well-being of LBLG, and (d) explore ways to integrate both types of care into the planning and implementation of culturally congruent care within South Sudanese LBLG communities throughout the United States. Achieving these goals was seen as vital in assisting nurses to plan and implement nursing care decisions and actions for the LBLG and possibly other South Sudanese refugees living in the United States.

The domain of inquiry for this study was the culture care beliefs, meanings, and practices related health and well-being of South Sudanese LBLG refugees within the



context of their lives in the midwestern United States. The ethnonursing method was used to discover the emic views of the LBLG related to the domain of inquiry. Etic observations of the researcher also contributed to the findings of the study. The researcher has been a participant for over 8 years within the environmental context of the LBLG community. Two years were spent in a volunteer role as a mentor for four young men newly arrived from Kakuma. As a result of these close relationships, many more grew, leading to active participation within the community. This prolonged immersion experience, along with time spent in research and extensive data collection, have contributed to the substantiation of evidence related to the qualitative research criteria of credibility, confirmability, meaning-in-context, recurrent patterning, saturation, and transferability.

The discussion of findings in this chapter will focus on patterns and themes discovered in relation to the domain of inquiry. Data were analyzed using Leininger's Four Phases of Ethnonursing Analysis of Qualitative Data (Appendix 5). This process began with documentation and analysis of all data, including verbatim descriptors and participant observational experiences. Verbatim descriptors presented in Chapter IV provided depth and clarity to the categories of environmental context, kinship and social factors, cultural values and lifeways, religious and spiritual factors, economic factors, educational factors political and legal factors, technological factors, meaning of health and well-being, maintaining health and preventing illness, health seeking behaviors, barriers to care and experiences with professional care. Data were then searched closely for patterns and meanings in context to support the domain of inquiry. In the fourth and final phase of data analysis the researcher abstracted and confirmed three major themes

from the categories and patterns. The thematic findings reflected the perception of the LBLG in regard to the domain of inquiry. They provide the knowledge necessary to guide nursing decisions and actions related to the provision of culturally congruent care.

The three major themes that emerged from this study were (a) spiritual care, grounded in a belief in the strength and wisdom of one God is health promoting and illness preventing; (b) contributing to and meeting the expectations of the community are necessary for health and well-being; and (c) The conflicting expectations of two cultures are affecting health and well-being. These themes are grounded in emic data and reflect the voices of the LBLG who participated in the study. In the following sections each theme will be presented and substantiated by supporting patterns and descriptors. The three predicted modes of nursing care actions and decisions related to the culture care theory will be presented as identified and abstracted from the patterns and themes to support culturally congruent care for LBLG living in the United States.

## 5.2 Presentation of Themes

### 5.2.1 Theme One

*Spiritual care, grounded in a belief in the strength and wisdom of one God, is health promoting and illness preventing.* The patterns that supported this universal theme were (a) a pattern of belief in a powerful, omnipresent God; (b) a pattern of living life sustained by hope; and (c) A pattern of communal interdependence and care.

The pattern of *belief in a powerful, omnipresent God* was supported by the responses of all informants. The LBLG referred to God frequently throughout the interviews, with references occurring in all categories with the exception of technological

factors. A word search for *God* in interview transcriptions revealed 161 occurrences, far more than any other word appearing in informant responses. LBLGs described a personal relationship full of love and respect for a benevolent God, whom they consider to be an integral part of their daily lives. Comments made by informants included the following:

- “Belief is one between you and God.”
- “God always guided me through all of this and I know He is there for me.”
- “We know the only person who is powerful that will be familiar with what we are doing is God.”
- “God gave me an instinct that inspired me to be there for Him no matter what. There’s not a day that I get up without calling Him. If I forget to call him that means I am in trouble [quiet laughter].”

In a follow-up survey on the adjustment of the unaccompanied minor LBLG both 3 months and 6 months after their arrival in the United States, Duncan (2001) noted that a belief in God continued to provide meaning to the lives of the LBLG. Goodman’s (2004) study with unaccompanied Dinka refugee youth (“lost boys”) 6 to 12 months following their arrival in the U.S., discovered that the youth interpreted their life experiences through a belief in the power of God’s will. Knowing that God was in control, and believing that they were alive for a reason, provided meaning to their lives. These findings from studies completed after the LBLG arrived in the United States are congruent with the findings of this study, in which informants expressed the purpose and meaning in their lives through their belief in God. A key informant described his understanding of the strength of God’s will:

If you look at some of us then we are in a big group, and then only you among those people, you are the only person alive. Sometimes you ask yourself, why me,

that I am the only person and the rest are not there? Then when you answer those questions, then you don't need to give up, because you believe that God wants to use you as a tool, maybe to bring change to other peoples' lives. You don't know, but God has a purpose for you.

Informants spoke repeatedly of placing their faith in God to provide strength, protection, and guidance through good times and bad, in health and in illness: "Nobody else but God gave me strength. When I ask something at the end of the day I get the answer. I believe without Him, I won't even exist and knowing that, I always ask for help." Several of the descriptors in Chapter IV describe informants' perceptions of God's interventions in guiding the LBLG to safety during their flight and struggles during exile in Africa. Informants also described many specific situations when God protected them during times of great difficulty or illness while living in the United States. A key informant shared,

If you really believe in God and you respect him that he's all knowing, he's all powerful, he won't give you something that you cannot handle, then you probably won't be crying a lot about being sick and all that.

Prayer is an integral part of daily life for the LBLG and was the most frequently observed and reported spiritual practice. Prayer is understood to be a direct form of communication with God and was reflected in the religious symbols in many homes. When visiting informants' homes the researcher observed biblical passages displayed on walls, including framed copies of the Lord's Prayer. Many informants wore crosses around their necks, and several reached for easily accessible Bibles which they referred to during the interviews. On several occasions the TV was tuned to a religious channel during the interview. Informants used the word *pray* frequently when speaking, regardless of the topic under discussion. Frequently heard phrases included "I pray to

God that . . .” and “Thank God for . . . .” A key informant described the importance of prayer in his life:

I express my religion by prayer . . . and in prayer, whenever I have a difficulty that is the time that I will say okay, how can I change? Those are the things personal, your personal life. Those are the things I believe on, when I pray I will be getting better for what I want to be; so those are the things that I am.

Another way that the LBLG expressed their respect and love for God was by choosing names of their own from the Bible at the time of their baptism. When the LBLG arrived in the United States, the vast majority had English Christian names on their documents. There was a preponderance of biblical names, including Peter, Moses, James, Abraham, and Rebecca. Many of the older lost boys in particular shared the story of their baptism. A key informant described this time:

The lost boys were in Pinyudo. That’s the time that everybody would say okay, how can you survive this jungle without anything? There is a God. And there were a lot of thousands of lost boys that were baptized, and each of us chose a name you need to be Christian. They would say, you have to pick the name in the Bible, what somebody do in the Bible; like me I chose William. Then they say what William did. William was a translator, he translate the Hebrew to English Bible, so most of us pick the name John, Peter, they should pick the name because of whatever somebody do in the Bible. And that’s when a lot of us were baptized and I became a Christian. From that time up to now just I’m a Christian and I believe in God and that’s where my religion is.

The pattern of living *life sustained by hope* was universal among informants. Experiences of war, living in refuge, and adapting to life in the United States contributed to this pattern, as did ongoing concern for families in Sudan and feelings of responsibility to contribute to the emergence of a new, stable South Sudan. Informants described a coping strategy focused on facing the future hopefully. Many related that while they do become frustrated when change can not be accomplished quickly; they remain hopeful that with time and perseverance, the safety and prosperity they dream of for their loved

ones and homeland will become a reality. As expressed by a key informant, “Without hope, life will be meaningless.”

Goodman (2004) found that maintaining hope for a better future helped the boys to endure the hardship and boredom of the refugee camps, ultimately contributing to their survival. Hope remained a motivating force following their arrival in the U.S. This is consistent with the emphasis placed on the importance of hope expressed by informants in this study. Several LBLG credited their ability to hold onto hope as the key factor in giving them the strength and patience necessary to endure hardship. They described a positive relationship between hope and perseverance, with hope providing the stamina and spirit necessary to persevere through hardships, both past and present. A key informant described how holding on to hope allowed him to persevere in his goal of coming to the United States:

When we lived in Kakuma, we have talked about hope a lot because it is only hope that let people come over here. Many of us just—they lost the hope. You can choose to go back to Sudan and live in the war, or you can choose to suffer a lot with diseases and no food and no good water and live in a camp and have opportunities to come to the United States. That is where I put having hope . . . I will call it hope of people thinking that they want something different in their lives. So people keep suffering and they think maybe one time, one day, things will change. That kept them in the camp for 9 years or more and they still made it to the United States. I know hope is when you just make what you want to happen; regardless of the difficulty you go through with it. You just have that powerful heart and wait for it. So that is how I see it, otherwise sometime, we may speak of hope because we are waiting, we’re really waiting.

Many informants expressed that they felt stronger and were able to maintain a sense of hopefulness, as a result of their belief in God. One informant shared that people have hope because

there is somebody out there. I know today I’m suffering, I might be suffering tomorrow, but at the end of the day, I’m still believing I’m going to be okay. That’s why sometimes some woman can get one kid die, second one die, third one

die, but they never give up because they know out of ten, two kids might be alive, and they keep on believing.

As another informant noted, stories of God's goodness continue to be passed on in the oral tradition, providing hope:

People hear histories of how God has been helpful to some people that have been through that kind of sickness and all these kind of things. You know, it gave people hope and expectation of miracles, to get them out of that.

Several informants noted an inverse relationship between hopelessness and well-being. Hopelessness can impair health, and in extreme situations lead to death. Those who lose hope no longer dream of a better future, they no longer persevere in reaching their goals, and they may withdraw from the community. One informant's comment illustrates the strength that comes with hope, and the despair that results from its loss:

To me, my definition of hope, everything is hope. You go to school, like, "Oh, okay. I want to be this. I want to be a pilot. I want to be a lawyer." You're hoping to be wherever, and the hope is the fire that keeps you going. If you lose that, you'll crash, and you're like, "Oh, life has no meaning. Going to school is a waste of time." You'd just sit around and just be nothing. So, I think, hope is what keeps your energy up there. So, we tend to go there. Keep going there, and tomorrow, maybe, will be a better day, or maybe will be a different day from today.

Another informant described the devastating impact that hopelessness may have on health:

When I was in the refugee camp, there were some people there who lose hope because they hear the bad news every time . . . They say that this is the end of life . . . Those people they just feel like why are they here, why are they in difficulty always. These are the only things that are in their minds. And that one some times, if somebody is thinking about the bad things that happened everyday, sometimes when there is anything that can affect the blood something like malaria or any disease, that person can die right away because they do not have hope or strong feeling that can keep them strong.

The final pattern that supports this theme is *communal interdependence and care*.

As mentioned earlier, strong kinship ties connect many of the LBLG with one another and with family living throughout the diaspora. In addition, LBLG formed a forceful

bond among themselves in their early years in refuge, and these ties remain strong in the United States. They have also maintained strong cultural and religious values that emphasize the obligation to care for and support one another in times of need. This care and concern is shown through being present with one another when someone is troubled or ill and joining together in prayer. This is equally beneficial whether it is one or two friends attending to the spiritual needs of a friend, or when an entire congregation prays for the return to health of someone within the community who is ill. One informant noted that when someone is ill,

The church will pray for him, like in the church, what they do in Sudanese is when they pray, when they want to close the church to prayer, people pray generally, personally, the people pray in the book, and in the long run at the end of the prayer they will say, "We will pray for Majier, he is sick," so everyone will pray for me whether I'm in the church or outside, they will pray for me. And that's what they do. So, if such friends are around that they want to see you they will come to your house and say okay we want to say hello to Majier. And they will come and say, and sit with me. If they feel that they want to pray, it is better, they will pray. But if they don't they will come and visit and talk to me and they will leave.

Communal religious practices such as prayer, reciting scripture and attending church services were described as sources of physical, mental, and spiritual well-being by informants. There were many descriptions of friends who were ill gaining strength from the presence and prayer of others. A young man described the wonder that is part of praying and his faith in God's will:

I cannot explain it. It's just a personal thing. You just pray to God that my friend will be well. So in your heart you pray. And if God hears you, he or she might be OK. And it cannot be explained. It's nothing to be seen. You believe it.

Another informant said that prayer is helpful when one is faced with difficult choices.

While God may not provide all the answers, the act of praying can result in a decision



about the best course to take. He went on to share how prayer may help those who are sick or faced with difficult circumstances:

If somebody is ill, if I go and visit, what I can do is to pray for him . . . In the religion I am, what we believe is when you see somebody who is sick or who goes to jail, is just to hold hands and pray for him.

While physical and medical care may be important for healing, spiritual care was described by numerous informants as crucial for the full recovery of the individual. The presence and care of family and friends who share the word of God is seen as an essential caring practice by the majority of the LBLG. A key informant noted that

Some people, when they are sick, they may ask somebody to pray for them. I remember somebody called a chaplain; I believe he was from the Episcopal Church. This friend told me, you know people used to come to me and say you eat, you eat, but nobody came and said the word of God, so it was like his spirit was going down. Yea, I remember a time when he was having diarrhea and he say, people come and say, here eat, take something, drink some water, but nobody had said something to do with the spirit . . . So, I think it is important. There are some people who also need to be nourished spiritually, other than our normal feeding that may raise the body, the spirit also needs to be fed.

## 5.2.2 Theme Two

*Contributing to and meeting the expectations of the community are necessary for health and well-being.* The patterns that supported this universal theme were (a) a pattern of honoring traditional values, (b) a pattern of communal interdependence and care, (c) a pattern of living life sustained by hope, and (d) a pattern of thinking too much.

The pattern of *honoring traditional values* was supported by the responses of all informants. On arrival in the United States, the living situation of this fledgling community was very different from traditional Dinka communities, where extended kin live in close proximity to one another. Several informants spoke of the isolation and loneliness they felt here, separated as they were from their extended kinship network.

Yet, even as they described their loss, they acknowledged that carrying the knowledge of what their family would have expected of them has continued to guide their behavior.

You do not have mom and dad. You do not have a brother and sister. You do not have other siblings; you do not have nieces and nephews. You do not have all of these but this structure of the family helps you sometimes. You will be a little bit ashamed, you won't allow yourself to do something that a little kid will criticize you for, and that can at least help you improve your health.

The LBLGs spoke of the importance of showing respect and loyalty to their families and places of origin, as well as protecting the history of their ancestors and family name. This was referred to by many as “maintaining good credits.” Living up to these communal expectations brings pride and reflects positively on themselves and the community. As one participant emphasized, “You have to have respect in my community.” Personal attributes reflecting honor, dignity, courage, pride and respect are important measures of an individual's place within the community. The importance of maintaining respect influences decisions and behaviors, and may encourage healthy choices. When poor choices are made, the opposite may occur. A key informant explained, “If I start veering straight from the ways which are expected in the community that would mean I am unhealthy.” The expectations of family and community may exert pressure on individuals to direct them away from behaviors that may bring shame to them all.

We let people know that your behaviors are being watched; you're like a father. This is what my father told me. He said, “People seem like they don't know you, or they act like they don't know you, but they know you in the top of their head. So if you do anything stupid, guess what, they are going to still remember that someday and use it against you at the time of marriage, so you have to be a good boy . . . you have to avoid doing unnecessary things such as drink at an early age.”

The pattern of *communal interdependence and care* discussed under the first theme was also reflected in the second theme. Many informants spoke of an obligation to

help those in need within the community. Simply being present at the time of need is one of the simplest, yet most important caring behaviors. A key informant stated, “I know if someone didn’t show up at an emergency situation that means you are not loved and to show up is a part of our duty.” Being present shows not only that one cares, but also shows respect for the honor and dignity of the individual and his family. Another informant shared,

We Dinka, the first thing from us, is respect. And, if you go to the Dinka community, the word help means something that you may find in everybody in our community. The Bible always talks about respect one another . . . You know not to do or not to involve in some of the crimes. So I think that’s the goodness. I mean it makes life healthy.

While it is acknowledged within the LBLG community that everyone is exceptionally busy, there is also an understanding that when someone is ill or otherwise in need of assistance, close friends will be informed so that they may provide assistance. According to a key informant,

It is good to tell out what you are suffering from if you’re going to be better . . . I think that will involve those who are my friends . . . as they say, “One hand can’t clap.”

The scope of communal care knows no physical boundaries, and may reach across vast distances to family and friends in Africa in the form of encouraging words delivered over the phone, or financial contributions to improve access to food or to travel to Nairobi for emergent health care. In describing his role in providing support to his mother and younger siblings in Sudan, one of the youngest informant’s comments illustrate the depth of responsibility he carries for his family, as well as the need within the LBLG community to hold on to one another for survival:

It’s my duty to keep my eye on them, so I am the one that actually—I am just like a father to the family. If I bring food to the table then I am there to raise them, because they don’t have jobs and the employment is zero. So, there’s no job,

there's nothing, so people just sit, see the days go over and over again. So, they have nothing to put their hands on to generate an income so they just live in a place like a house and that's it. They are powerless, and I know that I have been through it. So, it is something that is on the top of my mind. I know when they ask for help, I'm there for them and that's what I have seen people doing. I mean they're doing the same thing, we're uniform. We think alike; we do things the same way, it is because we have been brought up together as a group of people and our culture ties in too because people live close to each other and we try to hold on to one another because that's the only thing we have.

A further pattern that supports theme two is *thinking too much*. This phrase was used frequently by the LBLG when describing the behavior of someone experiencing a troubled emotional state. When asked if there was a Dinka word for thinking too much, a key informant replied "tak tak." He defined *tak tak* as "things that are in your mind that you want to solve but you can't find the right answers to solve them." He further amplified this by noting that *tak tak* is "a lost feeling, you know you have problems, you don't want to give up, but you can't find the right answer to solve it." Many factors were described as contributing to thinking too much, including memories of past experiences and losses and concerns about being unable to adequately provide for the needs of family. For many of the LBLG, there is much that they would prefer to forget but cannot. One informant described the recurring thoughts experienced by many:

People are still thinking about their parents because many of them are the only ones left in their family. Some of them never saw the remains from their families in the disaster that happened. Most of us, even when you are in a class or in your house or you are at work, you have thought about it. The whole thing will come in your mind all the way, like when you record a tape you have to go back, rewinding and all this. The mind was rewinding everything until they stop; when it will stop then your mind will relax a little bit.

Several informants expressed dismay that so many young men in the community are turning to alcohol as a means to stop thinking and forget their pain. One shared that,

You are thinking very much like your people are not that good and what do you want to do about it. A lot of young kids that came here, they see the counselors almost all the time. It made a lot of kids to drink a lot because in Dinka what they say is, you know if you ask somebody, why do you drink beer or why do you

drink liquor or wine? They say it in Dinka, and it means, whatever's in my head when I drink, I forget.

Concern for family at home, and for the future of South Sudan, also contribute to thinking too much. According to a key informant, sometimes the only way to cope is to isolate oneself, cocooning oneself away from all that is bad:

The life experience that I was being raised up by myself; raised up with no parents, no advice, nothing. Those are affecting us right now, through the thinking, through the frustration, through taking responsibility that you never dreamed about. Because coming to America is like, it sounds very good to all of us, but you are taking a responsibility that you never think it will be. Because you are taking care of the family, this is your real family, your uncle, your distant family. Everyone right now, when somebody is sick, they call you. When anything happens, they call you. And so this life it still in not easy; it is affecting some of us right now. Some of the boys, some of them take to drinking, because they think if I drink I don't think about anything anymore. I will not talk about my mom, wherever they are, whatever they're doing. They don't care about that. So those are the things. It is like a cocoon. It is like, somebody is staying in the small ground where you don't see anywhere, and you don't see light.

The final pattern that supports this theme is *living life sustained by hope*, which also influenced the first theme. As mentioned earlier, holding on to hope may provide the strength needed to persevere through difficult times. A key informant described a relationship between hope, community and health:

Everything we do here we do it with hope that something, someday, will go right in our community and that's what gives us the strength the most, regardless of all of the things that we encounter, and that can sometimes improve our health.

Informants also spoke to the powerlessness and hopelessness that they experienced when they were unable to help their families. While expectations for help were high, the LBLG did not have the resources necessary to do all that was requested of them. A key informant described the impact this perceived failure had on the health of many within the LBLG community:

Sometimes, when you see people are just being killed because they don't have any power to react back to that threat, you also feel unsettled. Like myself, I

would say, well, I'm here in America, a very free place where I can go to work, I can go to school. But a part of my body is back in Sudan, because my relatives are there, and they are suffering. They don't have a very good place. Also, my own place is there, it has been taken by those, because of the power they have. These are the problems; these are the sufferings people have here. The state of mind is the problem with most of the people here. Most people have that problem.

### 5.2.3 Theme Three

*The conflicting expectations of two cultures are affecting health and well-being.*

The patterns that supported this universal theme were (a) a pattern of communal interdependence and care, (b) a pattern of honoring traditional values, (c) an emerging reality of disruption in social balance, and (d) a pattern of thinking too much. The universal pattern of *communal interdependence and care* is integral to all facets of the lives of the LBLG, as evidenced by its contribution to each of the three themes that emerged from this study. As was discussed earlier, on arrival in the United States the LBLG focused on learning all they could of American culture. Initially many focused on finding the means to support themselves while continuing their education. As time passed, and the communication infrastructure improved in many areas of Sudan, the LBLG were successful in contacting many kin and friends who they had feared were dead. As individuals, and as groups made up of members of the same sub-clans, remittances were sent to help families who were returning to villages with limited access to food and other resources. Now growing numbers of the lost boys are married, and have started families. Expenses here have grown, and many are sending home smaller remittances than before, while others have made the difficult decision to use all that they have available to support their growing families. Informants described feeling conflicted as they strove to help their community in Sudan while providing for their own needs and those of their family in the United States. Their inability to provide for all who count on

them is having a profound impact on their health and well-being. As one key informant explained,

All these relatives, they're just looking on you, to say, "We are here, suffering here, suffering with sickness, suffering with anger. Just help us. Give us something." And, you find yourself, you have a family here, you're going to pay for that, and this, and car. And, when you just think about all these responsibilities, people become sick. You don't even think of getting something to eat, because you don't even have an appetite to eat. The problem has covered your feeling; it has covered your mind. And that's how the problem back home impact lives here, in America.

The pattern of *honoring traditional values* discussed in the second theme also provided support for this theme. Informants spoke of the challenges their community faces as they attempt to counsel those who have made choices that are outside of community norms. Traditionally elders within the community have stepped in to counsel and if necessary, place pressure on individuals whose behavior is unacceptable. One young man expressed frustration that some LBLG are not taking the advice of the elders:

People might run into some ways whereby if this was Sudan, they can't really be doing that. There will be older people calling you and sat you down. Even though you grow, I don't know, like a skyrocket or a big building, you know you still have to sit down in front of all the people. You have to have respect in my community. If you're tall like tall buildings you still have to sit down on the floor with older people and you have to listen to them.

Many LBLG are fearful that unhealthy behaviors learned in the United States will not only harm the individuals involved, but will be divisive to the community as a whole. Several informants cited concerns about increased alcohol use among LBLG, a behavior that traditionally is not acceptable until a man is married. Others noted that friends have received tickets for drinking and driving, and several have served jail terms resulting from multiple incidents of driving under the influence. As one informant explained, the traditional means of handling this type of behavior have not met with much success in the United States:

If this was Sudan and people are doing stuff like that, they (the elders) call them and sit them down and said OK, why you do this? You have to explain to them. And if you're wrong, then you don't have to do it next time. Otherwise there's going to be some punishment. But here, it's not there. And as the same age people, we can't really do that. So there are a lot of negative things coming into our community. And we can't change them because we don't have a voice and we don't have the power to take those people and say, "Ok, you shouldn't be doing this." So it's kind of tough. And it's just, you just kind of hope that that will end. But I don't know.

The third pattern supporting this theme is *an emerging reality of disruption in social balance*. Informants spoke openly of challenges that have resulted as they strive to find the right balance between honoring their traditional values and finding success in the United States. This dilemma is not unique to the LBLG, and has been well documented among many refugee and immigrant populations in the refugee literature (Chung, Bemak, & Wong, 2000; Davis, 2000; Lipson & Omidian, 1997; Miller & Chandler, 2002; Wehbe-Alamah, 2005). Informants described situations they considered untenable in which their values conflicted with established cultural norms in the United States. Most notably, informants' spoke of growing instability within marriages. As wives of lost boys arrived in the United States, many sought jobs outside the home to contribute to the family income. This resulted in a transformation of traditional gender roles, with women expecting a greater say within the family unit. As one informant described it, "Here in this country you do not have a voice to tell your woman and you need to be polite."

Major conflicts between spouses, traditionally resolved through discussion with extended family and elders, are now being forcibly resolved in court. Several informants shared their belief that the U.S. legal system is biased towards the rights of women over men, and is imposing solutions that promote the breakdown of marriages. While it is acceptable in their culture for a man to beat his wife for a grave misdeed, informants maintained that this is a rarity among the LBLG here in the United States. They voiced



concerns that women are claiming their husbands beat them, and in some instances are rewarded with an apartment, food stamps, work training, and sometimes daycare for the children. As one informant explained,

Back in the day if I have an issue with my wife, she will not call—well, we don't have 911, but she will not go to the Police Station or to anybody and say, hey! Madut . . . The only people that she will go to are my brothers or my uncles and then those people will call me and talk. But like in this culture if she is upset she just dial the phone . . . So, with this culture it turn things down a little bit and sometimes especially, we the men, we don't really appreciate it. Not like we don't respect this law, but when they are applied to us, its peril. We don't really go to the same direction. Like, if I have a problem with my wife and the kid has to be taken away or the wife will keep the kid, it's not over there. Or maybe we have money in the bank, and she have to take everything and all that. So, these are the things that are changing right now.

A key informant noted that a wife may use her freedom in the United States to challenge her husband's authority. He shared a recent situation example that occurred in his community:

They have the right to call 911, and I heard one case where a father beat his son or his child. And his wife called 911. He was taken to Kent county jail. So what they did, they took him to go and take classes, kind of like orientation, you know, to say you don't have to beat child here and all that. But back home what they do, in Sudan, no 911. What they do if you are a bad husband or a husband that don't be involved with your wife, the wife has a right to talk to your parents and report you to your parents, and say that you are mistreating her and explain the situation and parents look into that reason and call other family members and call you. And that will be like a punishment.

Another concern facing the LBLG is how to raise strong children in the United States, where the educational and legal systems do not condone the use of corporal punishment. One way to show parental love is to punish behaviors that are unacceptable within the culture. Informants told of teachers notifying protective services when a child's response to questioning indicated that he or she had been hit. Stories were also circulating of children calling 911 to report their own parents. Parents were concerned

their authority was being usurped. More importantly, they worried that their children would not learn to behave in the manner expected within their community.

*Thinking too much*, which also supported the second theme, was the final pattern identified in support of this final theme. The majority of informants provided descriptions of thinking too much, and offered many examples of situations that contributed to this state. The etiology most often identified for thinking too much was having problems to which no solutions could be found. Situations such as those discussed in the previous sections, the result of failed attempts to meet the conflicting expectations of two cultures, were identified by many as precursors to *thinking too much*. Among the many serious symptoms of *thinking too much* were feelings of powerlessness, depression, anxiety, fatigue, shame, hopelessness and despair. Informants repeatedly shared that while living at Kakuma, they held out hope that sometime in the future they would be able to build a better life in the United States. Yet, for some, that has not been their experience.

Within the local LBLG community, support is available for many of those who feel they have failed to meet the standards expected of them in their roles, including those of community organizer, parent, employee, student, and elder. A religious leader shared that there may be greater support and understanding among LBLG living in the United States, than that received from those who have little knowledge of the culture here. It is difficult for those who have never lived in the United States to understand the outside conflicts that may break up a marriage, or result in a jail sentence. A community leader provided an example of the pain that may result when someone who is honoring traditional cultural norms loses what he or she loves most:

We had one incident, I've been on the Southern Sudanese Community Board of Directors for a long time, you know. And one thing that we do if we know there

is, you know, domestic violence or there is going to be a divorce, it's something that Sudanese are not very comfortable with. When a woman divorces a man, you tend to see yourself that you're not good man enough, you're not good enough. And a lot of people are really are in that dramatic situation. So we had one incident a couple of years ago. And the guy was so hopeless. He didn't want to go to work. He didn't even want to see anybody. He felt so bad because his wife divorced him. So what we did as a community, we organized ourselves and we went as a group. You know, we spent a day in his apartment and we cheered with him and we empowered him that, "This is not the only thing that you have. You have so much to give to our community. You have so much to do for yourself. You have so much to do for those kids. Regardless of where they are with their mother you're still the father. Sudanese people still recognize that it wasn't your fault. It's just a new culture and the clash of cultures and people are more free here. People want too much freedom. And there are so many laws around that you can't do anything. So the best thing that you can do is to do well to prove that you were good enough." And you know what, he recovered.

The three substantive themes that were identified in this study are complex and interrelated. For the LBLG, health means being able to contribute to and meet the expectations of the community. The conflicting expectations of two cultures make this a challenging endeavor. They strive to honor their families and country by leading exemplary lives reflective of their traditional values. As a group, the LBLG shoulder a heavy burden as they make personal sacrifices to provide support and leadership to family and extended kin much less fortunate than themselves. Throughout this struggle, the LBLG are buoyed by the support of their community, a strong faith in God, and the hope of better times to come.

### 5.3 Discussion of Culturally Congruent Nursing Care

According to Leininger (1991), diversities and similarities in care exist both within and among all cultures of the world. This knowledge is best elicited from the emic perspective of the people themselves. Utilizing Leininger's culture care theory, this study discovered the culture care meanings, beliefs, and practices related to the health and well-

being of South Sudanese LBLG refugees living in the midwestern United States. The discovery of the culture care practices of the LBLG should provide nurses with the knowledge necessary to make care decisions and initiate care actions that are culturally congruent with the beliefs and practices with the LBLG community. In accordance with the culture care theory, these decisions and actions are guided by three modes of care: (a) culture care preservation and/or maintenance, (b) culture care accommodation and/or negotiation, and (c) culture care repatterning and/or restructuring.

### 5.3.1 Culture Care Preservation and/or Maintenance

In order to preserve and maintain meaningful care values for Sudanese LBLG, nurses and other health care providers are encouraged to integrate the following practices into their care.

1. *Take time to welcome and greet.* Greetings are an important first step in forming a relationship and establishing trust. Greetings should be exchanged before saying anything else. A hand shake is appropriate and expected when greeting a man, regardless of the gender of the health care provider. Avoid jumping immediately into questions of a medical nature. Most LBLG want to form a connection with their health care provider, and this is difficult to do without knowing something about who that provider is, and being assured that the provider values him or her as a person, not just someone with a problem or illness.

2. *Respect cultural beliefs and values.* The first step to understanding the beliefs and values of others is to recognize one's own cultural values, beliefs and biases. Showing an openness to learn about and accept differing cultural traditions related to

kinship and marriage, child-rearing practices and mental illness among others, will foster the trust and respect which are precursors to open communication.

3. *Provide frequent encouragement.* Encouragement fosters hope. The nurse can provide encouragement by noting each small improvement, sharing stories of others who have overcome similar circumstances, pointing out personal strengths that may be drawn on to enhance healing, and depending on the situation, sharing that healing is a process, and that with time, the person will be well again. Encouragement demonstrates care for the person, and contributes to feelings of security and well-being.

4. *Acknowledge spiritual rituals.* Spiritual and religious beliefs and practices are integral to the lives of the LBLG. It is important that the nurse ask what can be done to promote the spiritual health of the individual. If hospitalized, permission may be sought to invite the hospital chaplain and/or the individual's minister or priest to visit and pray. Use of a Bible may be appreciated by those who are without one. Some LBLG would appreciate the nurse praying with them if they share a similar faith. Faith, prayer, and belief in the power and beneficence of God are vital for the maintenance of health and well-being.

5. *Provide specific education that will promote health and healing.* Health care providers are generally respected for their knowledge by the LBLG community. There is an expectation that health care providers will offer advice that will promote healing, or will prevent future illness. When no advice is offered, there may be concern that there is nothing that can be done for the person who is sick. A lack of advice may also be perceived as a lack of respect or care for the individual. When health education is

provided, it is received as health advice, and is taken seriously because health care providers are considered to be experts in their field.

6. *Maintain a caring presence.* Within the LBLG community, being present when a friend or family member is sick is the most important act of caring. A nurse who appears unrushed, and remains focused on the individual requiring care, will most often be perceived as caring. Checking in on an inpatient LBLG regularly is a form of caring. A community based nurse who takes time for a home visit will be respected for caring.

7. *Honor privacy when addressing culturally sensitive concerns.* This is of the utmost importance when addressing questions related to behaviors considered private or taboo, including reference to reproductive health, sexually transmitted infections and mental illness. Care must be taken to express the rationale for such questions, and to ask them in a private setting to minimize distress or embarrassment.

8. *Assure that confidentiality of information provided to health care providers is maintained at all times.* This is essential to maintain trust within the LBLG community. It is appropriate to ask whom, if anyone, the LBLG wishes the health care provider to share information with.

### 5.3.2 Culture Care Accommodation and/or Negotiation

In order to accommodate for or negotiate cultural care for Sudanese LBLG, nurses and other health care providers are encouraged to integrate the following practices into their care.

1. *Negotiate for same gender health care providers and translators when discussing sensitive issues, particularly related to sexuality and GI function.* While many LBLG are accepting of opposite gender health care providers for general care, they often

prefer a same gender provider when issues related to reproductive, gastro-intestinal or urinary function need addressed. Women in particular may prefer a female health care provider and translator. It is important that the nurse ask directly about gender preferences, and negotiate for appropriate staff assignments to accommodate such preferences.

2. *Listen attentively and patiently.* The LBLG live in a high-context culture, where the relationship is more important than anything else. Much background information may be shared before the point of the discussion is reached. When a sensitive issue is being addressed, it may be referred to indirectly or ignored altogether. Mindful listening and clarification are essential to picking up clues to the underlying issue being addressed. Most of the LBLG perceived health care providers who were too rushed or distracted to listen attentively as lacking respect, uncaring and/or incompetent. The nurse may negotiate with colleagues to cover other responsibilities, allowing for segments of uninterrupted time. Listening and caring are so intertwined that attentive listening was described as “listening with your heart”.

3. *Allow for the presence of many visitors.* Presence is the foundation of caring. When LBLGs learn that a friend is ill, being present is both a need and an obligation. Prayers may be offered, encouragement given, and the distraction of positive stories and even jokes may be shared. Noise levels that may otherwise disturb others may be avoided by providing a private room, closing the door, or explaining the need for quiet, so that others may rest and heal. Friends who have lived in close proximity since childhood are as important as family, and should be welcomed at the bedside, even at times of severe illness. Many LBLG have work and school commitments which may preclude them from

visiting during set visiting times. Accommodating visitors who may or may not be family at the times when they are available to visit will contribute to the well-being of those who are ill.

*4. Negotiate for the provision of qualified translators, of the same gender and belonging to the same ethnic group as LBLGs who do not communicate well in English.*

While the majority of LBLGs speak excellent English, the stress of an acute illness, an unfamiliar environment, and a lack of experience with medical terminology and procedures, may necessitate the provision of a qualified translator as a cultural broker. The nurse will need to negotiate with administration for a same gender translator. Failure to do so may result in the failure to provide vital information. The translator may also be placed in the difficult situation of living in a close community with the person he or she is providing translation for, while being privy to knowledge that is culturally inappropriate for him or her to know. Many LBLG are fluent in multiple languages, including Swahili. A translator of another ethnic group who speaks Swahili may be able provide translation, but may lack the knowledge necessary to explain important cultural implications.

*5. Provide for basic care needs.* When a LBLG is ill enough to require hospitalization their expectation is often that they will need assistance with most of their activities of daily living. The nurse should ask what assistance is required, and provide comfort care. Family and friends may wish to assist with physical care, including bathing and feeding. In situations where activity is important for the restoration or maintenance of function, the rationale for the need to sit in a chair, ambulate and participate more actively in other activities of daily living should be shared with the LBLG. An



understanding of the benefits of participating more actively in self care will minimize perceptions that the nurse is not providing adequate care.

### 5.3.3 Culture Care Repatterning and/or Restructuring

In order to repattern or restructure some of the potentially negative health practices of the Sudanese LBLG, nurses and other health care providers are encouraged to integrate the following practices into their care.

1. Collaborate with LBLG community and religious leaders in identifying areas of concern regarding the health and well-being of the community. Collaborate in the development of educational programs that will be provided by trusted South Sudanese leaders and health care providers in a way that honors cultural values while promoting the safety, health, and well-being of community members.

2. Teach the dangers of medication sharing and reliance on over the counter medications. Many LBLG do not have health insurance, and only seek health care when they are too ill to attend work or school. Many reported relying on over the counter medications which contain Aspirin or Acetaminophen. Explain complications which may result from over consumption of either medication, and how to read labels to keep track of safe dosages.

3. Encourage the LBLG community to discuss the importance of selecting a person they trust to make health care decisions if they become unable to do so themselves. Emphasize the legal importance of documenting a durable power of attorney for health care. For many LBLG, the person who they would wish to make medical decisions when they themselves are unable to do so is not their legal next of kin.

4. Educate the LBLG community about child rearing practices that are in conflict with U.S. child protection laws, and the consequences of not following them.

Acknowledge the shared goal of raising respectful, well behaved children. Mutually identify strategies for disciplining children that are culturally appropriate and are not in conflict with child protection laws.

5. Educate the LBLG community about the health risks that result from over consumption of alcohol. Focus on the harm that may be inflicted on others from drinking and driving and behavioral changes.

6. Educate the LBLG community about safe sex practices that prevent the transmission of sexually transmitted infections, including HIV/AIDS. Collaborate with male and female community leaders in the development of same gender programs, led by respected community members.

7. Provide the LBLG community with information about affordable local health care services.

8. Lobby political leaders to introduce legislation that will provide universal health insurance and regulate medication costs.

9. Promote the benefits of seeking medical attention before symptoms become severe. Many LBLG spoke of spending thousands of dollars on emergency room visits, when an earlier visit to a primary care provider may not only have prevented this, it would have been much more cost effective too.

10. Seek out, consult, and promote referrals to counselors and social workers who provide culturally appropriate mental health services within local South Sudanese communities, particularly those who are South Sudanese themselves.

11. Provide education about the health care beliefs and practices of South Sudanese refugees to health care providers who provide care in communities with South Sudanese populations.

12. Actively mentor LBLG who wish to enter health care fields.

## 5.4 Nursing Implications

### 5.4.1 Implications for Nursing Theory

This study was conceptualized within Leininger's theory of culture care diversity and universality, which provided a theoretical framework that guided the researcher in the discovery of culture care beliefs, meanings and practices related to health and well-being among South Sudanese LBLG living in the U.S. Midwest (Leininger, 1991). The breadth of the theory is evident in the stated assumption that "culture care values, beliefs, and practices are influenced by and embedded in the worldview, social structure factors (e.g., religion, philosophy of life, kinship, politics, economics, education, technology, and cultural values) and the ethnohistorical, and environmental contexts"(Leininger & McFarland, 2006, p. 19). The findings of this study supported this assumptive premise as evidenced by the emergent patterns and themes.

The three themes in this study, supported by patterns that reflect both universalities and diversities, support the assumptive premise that similarities and differences about human care exist among and within all cultures of the world. The challenges the LBLG faced following arrival in the United States, with hopes of prospering despite being members of a minority refugee population, have resulted in divergent views within the LBLG community. One of the emergent themes, *the*

*conflicting expectations of two cultures are affecting health and well-being*, speaks directly to this diversity. For instance, some parents are continuing to discipline their children as they were disciplined themselves, while others are avoiding corporal punishment as required by the child protection laws where they now live. Regardless of the choice made, a universality identified in this study is all parents strive to raise respectful, well-behaved children.

A further assumptive premise confirmed with the findings of this study is that “care is essential to curing and healing, for there can be no curing without caring (Leininger & McFarland, 2006, p. 18).” Caring is a communal responsibility for the LBLG and is prerequisite to the recovery of health. Many of the generic caring practices which emerged in this study focused on the integration of individual and community. Communal presence during illness, offering prayers, sharing stories, and giving advice were among the emergent generic caring practices which strengthened communal bonds. An understanding of the essential nature of communal interdependence and care among the LBLG is prerequisite to the promotion of health and well-being and the provision of culturally congruent care. The specific culture care beliefs, meanings and generic caring practices of the LBLG identified in this study contribute to transcultural nursing knowledge and provide a foundation for further study.

#### 5.4.2 Implications for Nursing Education and Practice

This study supports the inclusion of culture care knowledge in nursing and other health care curricula. It is often assumed that culture is integrated throughout nursing curricula, when the reality is that frequently only general core concepts, or a survey of health care beliefs and practices of a few, select cultures are included. As the United

States becomes more and more diverse, it is imperative that specific transcultural nursing research findings and practices are made explicit and reinforced throughout the undergraduate curriculum. It is anticipated that the inclusion of the findings of the culture care beliefs, meanings and practices identified in this study will assist both student and professional nurses in the provision of culturally congruent care for the LBLG.

The findings from this study provided emic meanings of health beliefs and caring expressions among the LBLG. While the LBLG represent a relatively small, minority population in the United States, nurses must become familiar with their health care beliefs and caring practices before they are able to provide culturally congruent care. Nurses who are familiar with the vital role the LBLG community plays in maintaining health and preventing illness will be prepared to focus on community interventions rather than focusing solely on the individual alone. Nurses who understand that seeking professional care is often a last resort because of financial and cultural circumstances will be prepared to demonstrate respect, appear unrushed, complete a thorough assessment and anticipate the need to follow-up with a home visit or phone call whenever possible. Nurses who recognize the strength that results from a belief in God will be prepared to incorporate spiritual caring practices. Nurses who have knowledge of the culture of the LBLG are prepared to recognize the universalities that exist among us, and value the diversities, rather than focus on and judge any behaviors that are different from one's own. This knowledge is vital if nurses are to focus on the inclusion of generic caring practices in the delivery of professional nursing care to the LBLGs they serve.

### 5.4.3 Implications for Nursing Research

The findings of this study demonstrate the effectiveness of the ethnonursing method and Leininger's culture care theory in teasing out the evolving health care beliefs and practices of one specific group of unaccompanied minor refugees, the lost boys and lost girls of Sudan. The use of Leininger's Observation-Participation-Reflection enabler, which guided the data collection process, has been shown to increase the validity and reliability of research findings by strengthening the skills, cultural awareness and cultural sensitivity of the researcher. The researcher spent significantly more time developing trust and gaining entry into the LBLG community than in the interviewing process itself. The findings of this study underscore the vital role knowledge of the emic perspective of informants, as well as the etic perspective of outsiders, play in the development of culturally congruent care.

The findings of this study contribute to the growing body of transcultural nursing knowledge which addresses the health care beliefs and practices of recently arrived refugee and immigrant populations in the United States. This study was the first to explore the culture care beliefs, meanings and practices related to health and well-being of the LBLG within the context of their lives following resettlement in the United States. Culture is not static, and the study results provide evidence that the LBLG, who are now adults, have begun the process of acculturation experienced by many other immigrant and refugee groups as they adapt to life in the United States. Replication of this study with South Sudanese men and women of the same generation as the LBLG in South Sudan and other nations of the diaspora will identify the influences of acculturation on culturally congruent care. Replication with other age sets of both genders will lead to the discovery

of the influence age and gender have on culturally congruent care. Finally, replication with other African immigrant or refugee groups living in the United States is necessary to identify the health care beliefs and practices related to health and well-being of these minority populations. Further foci for future studies which could increase nursing knowledge of cultural care for the LBLG include the following:

1. What is the relationship between the political situation in South Sudan and the health and well-being of the LBLG?

2. Which generic caring practices nurture hope in the LBLG?

3. What is the relationship between spiritual caring practices and health and well-being of the LBLG?

4. How can access to and satisfaction with professional health care systems be improved within the LBLG community?

5. Which cultural influences and generic caring practices influence “thinking too much” in the LBLG community?

6. How do shifting gender roles influence the health and well-being of the LBLG community?

7. What is the effect of acculturation on the culture care beliefs, meanings and practices related to the health and well-being of the LBLG?

## 5.5 Conclusion

This study investigated the culture care beliefs, meanings and practices related to the health and well-being of South Sudanese “lost boy and lost girl refugees” living in the Midwest United States. The informants’ receptiveness to the study was evident in their

eagerness to introduce the researcher to friends and community leaders, and the encouragement and support which were offered when enquiring about the progress of the study. The study was conceptualized within Leininger's theory of culture care. The ethnonursing method was used as a guide to the discovery of the emic perspective of the LBLG in relation to health, well-being, and culture care, which is essential for the development of culturally congruent caring practices. In addition to answering the research questions, three themes and six patterns that emerged from the data were discovered and discussed. The findings support the importance of understanding the influence of cultural context, values and beliefs in the provision of culturally congruent care. Implications for nursing theory, education and practice, and research for planning and implementing culturally congruent care to LBLG were presented. It is the researcher's hope that the transcultural nursing knowledge discovered in this study will assist in the provision of culturally congruent and meaningful nursing care which will support the health and well-being of a generation of young South Sudanese refugees relocated to the United States as a result of the devastation wrought by war in Sudan.



## REFERENCES

- Abusharaf, R. M. (2002). *Wanderings: Sudanese migrants and exiles in North America*. Ithaca: Cornell University.
- American Nurses Association. (2003). *Nursing's social policy statement*. Kansas: American Nurses' Association Publications.
- Bagenda, E., & Hovil, L. (2003). Sudanese refugees in Northern Uganda. *Forced Migration Review*, 16, 14-16.
- Barnes, D., Harrison, C., & Heneghan, R. (2004). Health Risk and Promotion Behaviors in Refugee Populations. *Journal of Health Care for the Poor and Underserved*, 15, 347-356.
- Bateman, G. (Ed.). (2002). *Encyclopedia of world geography*. San Diego, CA: Thunder Bay Press.
- Bates, L., Baird, D., Johnson, D. J., Lee, R. E., & al, e. (2005). Sudanese Refugee Youth in Foster Care: The "Lost Boys" in America. *Child Welfare*, 84(5), 631-648.
- Berman, H., Giron, E., & Marroquin, A. (2006). A narrative study of refugee women who have experienced violence in the context of war. *Canadian Journal of Nursing Research*, 38(4), 32-53.
- Beswick, S. (1998). *Violence, ethnicity and political consolidation in south Sudan: A history of the Dinka and their relations with their neighbors*. Unpublished Doctor of Philosophy, Michigan State University, Lansing, MI.
- Bixler, M. (2005). *The lost boys of Sudan: An American story of the refugee experience*. Athens, GA: University of Georgia Press.
- Bok, F. (2003). *Escape From Slavery*. New York: St. Martin's Press.
- Bolea, P., Grant, G., Burgess, M., & Plasa, O. (2003). Trauma of children of the Sudan: A constructivist exploration. *Child Welfare*, 82(2), 219-233.
- Bowles, M. (2005). *Culture care beliefs, meanings and practices related to health and well-being of Sudanese refugees*. Unpublished Unpublished, Duquesne University, Pittsburgh.
- Brink, P., & Wood, M. (2001). *Basic steps in planning nursing research: From question to proposal* (5th ed.). Sudbury, MA: Jones and Bartlett.

- Burgess, A. (2004). Health challenges for refugees and immigrants. *Refugee Reports*, 25(2), 1-3.
- Carolan, M. (2009). Pregnancy health status of sub-Saharan refugee women who have resettled in developed countries: a review of the literature. *Midwifery, In Press, Corrected Proof*.
- Central Intelligence Agency. (2006). *CIA Factbook: Sudan*. Retrieved September 11, 2006, from <https://www.cia.gov/cia/publications/factbook/geos/su.html>
- Chung, R., Bemak, F., & Wong, S. (2000). Vietnames refugees' levels of distress, social support, and acculturation: Implications for mental health counseling. *Journal of Mental Health counseling*, 22, 150-160.
- Corbett, S. (2001, April, 1). From hell to Fargo: The lost boys of Sudan land in America. *The New York Times Magazine*, 49-84.
- Davis, R. (2000). Refugee experiences and Southeast Asian women's mental health. *Western Journal of Nursing Research*, 22, 148-168.
- Deng, F. M. (1972). *The Dinka of the Sudan*. Prospect Heights, IL: Waveland Press, Inc.
- Deng, F. M. (1995). *War of Visions: Conflict of Identities in the Sudan*. Washington, D.C.: The Brookings Institution.
- Deng, F. M. (2003). *Revisiting tradition and modernization: A challenge for law among the Dinka of the Sudan*. Retrieved September 11, 2006, from [http://www.houseofnationalities.org/tradition\\_modernization.asp](http://www.houseofnationalities.org/tradition_modernization.asp)
- Derib, A. (2002). *Group care and fostering of Sudanese children*. Stockholm, Sweden: Save the Children Sweden.
- DeSantis, L. (1997). Building healthy communities with immigrants and refugees. *Journal of Transcultural Nursing*, 9, 20-31.
- Dicky, S. (Ed.). (2001). *Africa* (10th ed.). Farmington Hills, MI: Gale Group.
- Duany, J. A. (2003). *Making Peace & Nurturing Life: A Memoir of an African Woman About a Journey of Struggle and Hope*. Bloomington, IN: 1stBooks.
- Duncan, J. (2000a). *Overview of mental health findings for UAM and separated children*. Kakuma, Kenya: United Nations High Commissioner for Refugees.
- Duncan, J. (2000b). *Sudanese girls in Kakuma*. Retrieved September 21, 2006, from [http://www.mapendo.org/refugee\\_info/sudanese\\_girls\\_kakuma.php](http://www.mapendo.org/refugee_info/sudanese_girls_kakuma.php)

- Duncan, J. (2001). *Sudanese "lost boys" in the United States: Adjustment after six months*. Washington, D.C.: United States Catholic Conference.
- Evans-Pritchard, E. E. (1940). *The Nuer: A description of modes of livelihood and political institutions of a Nilotic people*. Oxford: Clarendon Press.
- Finnegan, W. (1999, January 25). The invisible war. *The New Yorker*, 50-73.
- Fitzgerald, M. A. (2000). *U.S. resettlement for Sudanese youth at Kakuma, Kenya*. Retrieved April 12, 2001, from <http://www.refugeesinternational.org/>
- Geltman, P., Grant-Knight, W., Ellis, H., & Landgraf, J. (2008). The "Lost Boys" of Sudan: Use of Health Services and Functional Health Outcomes of Unaccompanied Refugee Minors Resettled in the U.S. *Journal of Immigrant and Minority Health*, 10, 389-396.
- Geltman, P. L., Grant-Knight, W., Mehta, S. D., Lloyd-Travaglini, C., & al, e. (2005). The "Lost Boys of Sudan": Functional and Behavioral Health of Unaccompanied Refugee Minors Resettled in the United States. *Archives of Pediatrics & Adolescent Medicine*, 159(6), 585-591.
- Giger, J. N., & Davidhizar, R. E. (2004). *Transcultural nursing: Assessment and intervention* (4th ed.). St. Louis: Mosby.
- Goodman, J. (2004). Coping with trauma and hardship among unaccompanied refugee youths from Sudan. *Qualitative Health Research*, 14(9), 1177-1196.
- Harrigan, S., & Chol, C. (1999). *The Southern Sudan Vulnerability Study*. Nairobi, Kenya: Save the Children Fund (UK) South Sudan Programme.
- Hollifield, M., Warner, T., Lian, N., Krakow, B., Jenkins, J., Kesler, J., et al. (2002). Measuring trauma and health status in refugees: A critical review. *Journal of the American Medical Association*, 288, 611-621.
- Holtzman, J. (2000). *Nuer Journeys Nuer Lives: Sudanese Refugees in Minnesota*. Needham, MA: Allyn and Bacon.
- Howard, M., & Hodes, M. (2000). Psychopathology, adversity, and service utilization of young refugees. *Journal of the American Academy of Child & Adolescent Psychiatry*, 39, 368-377.
- Human Rights Watch. (2003). *Part I: Oil in Southern Sudan*. Retrieved July 11, 2006
- Human Rights Watch/Africa. (1994). *The Lost Boys: Child Soldiers and Unaccompanied Boys in Southern Sudan*. New York: Human Rights Watch.

- Hutchinson, S. (1992). 'Dangerous to eat': Rethinking pollution states among the Nuer of Sudan. *Africa*, 62(4), 490.
- Hutchinson, S. (1996). *Nuer Dilemmas: Coping with money, war, and the State*. Berkely and Los Angeles, CA: University of California Press.
- Hutchinson, S. (2001). A curse from God? Religious and political dimensions of the post-1991 rise of ethnic violence in South Sudan. *Journal of Modern African Studies*, 39(2), 307-331.
- International Council of Nurses. (2006). *Health Services for Migrants, Refugees and Displaced Persons*. Retrieved December 29, 2008, from [http://www.icn.ch/PS\\_A06\\_HealthMigrantsRefugees.pdf](http://www.icn.ch/PS_A06_HealthMigrantsRefugees.pdf)
- Jeppson, O., Nilen, H., & Tefferi, H. (1994). *The unaccompanied children of Southern Sudan*. Stockholm: Swedish Save the Children.
- Jeppsson, O., & Hjern, A. (2005). Traumatic stress in context: A study of unaccompanied minors from Southern Sudan. In D. Ingleby (Ed.), *Forced migration and mental health: Rethinking the care of refugees and displaced persons* (pp. 67-80). New York: Springer Publishing Company.
- Jok, A. A., Leitch, R., & Vandewint, C. (2004, March). *A study of customary law in contemporary Southern Sudan*. Retrieved August 30, 2006, from [http://www.gurtong.org/ResourceCenter/laws/Customary%20Law%20Overview%20in%20South%20Sudan%20March%202004\\_compressed.doc](http://www.gurtong.org/ResourceCenter/laws/Customary%20Law%20Overview%20in%20South%20Sudan%20March%202004_compressed.doc)
- Jok, J. M. (1999). Militarization and gender violence in South Sudan. *Journal of Asian and African studies*, 34(4), 427-442.
- Jok, J. M. (2001). *War and Slavery in Sudan*. Philadelphia: University of Pennsylvania Press.
- Jok, J. M., & Hutchinson, S. (1999). Sudan's prolonged second civil war and the militarization of Nuer and Dinka ethnic identities. *African Studies Review*, 42(2), 125-145.
- Kamya, H. (1997). African immigrants in the United States: The challenge for research and practice. *Social Work*, 42, 146-165.
- Keyes, E. (2000). Mental health status in refugees: An integrative review of current research. *Issues in Mental Health Nursing*, 21, 397-410.
- Leininger, M. M. (1991). The theory of culture care diversity and universality. In M. M. Leininger (Ed.), *Culture care diversity and universality: A theory of nursing* (pp. 5-65). New York: National League for Nursing.

- Leininger, M. M. (1996). Culture care theory, research, and practice. *Nursing Science Quarterly*, 9, 71-78.
- Leininger, M. M. (1997a). Overview of the theory of culture care with the ethnonursing research method. *Journal of Transcultural Nursing*, 8, 32-52.
- Leininger, M. M. (1997b). Transcultural nursing: A scientific and humanistic care discipline. *Journal of Transcultural Nursing*, 8, 54-55.
- Leininger, M. M. (1998). *Qualitative research methods in nursing*. Ohio: Greydon Press.
- Leininger, M. M., & McFarland, M. R. (2002). *Transcultural nursing: Concepts, theories and practices*. New York: McGraw-Hill.
- Leininger, M. M., & McFarland, M. R. (2006). *Culture Care Diversity & Universality: A Worldwide Nursing Theory* (Second ed.). Sudbury: Jones and Bartlett.
- Lienhardt, G. (1961). *Divinity and Experience: The religion of the Dinka*. London: Oxford University Press.
- Lipson, J. G. (1992). The health and adjustment of Iranian immigrants. *Western Journal of Nursing Research*, 14(1), 10-29.
- Lipson, J. G. (1993). Afghan refugees in California: Mental health issues. *Issues in Mental Health Nursing*, 14(1), 411-423.
- Lipson, J. G., & Omidian, P. (1997). Afghan refugee issues in the U.S. social environment. *Western Journal of Nursing Research*, 19, 110-126.
- Lustig, S., Weine, S., Saxe, G., & Beardslee, W. (2004). Testimonial psychotherapy for adolescent refugees: A case series. *Transcultural Psychiatry*, 41(1), 31-45.
- Matheson, I. (2002, June 2, 2002). *The "Lost Girls" of Sudan*. Retrieved March 3, 2003, from <http://news.bbc.co.uk/1/hi/world/africa/2031286.stm>
- Miller, A., & Chandler, P. (2002). Acculturation, resilience, and depression in midlife women from the former Soviet Union. *Nursing Research*, 51(1), 26-32.
- Muecke, M. (1992a). New paradigms for refugee health problems. *Social Science & Medicine*, 35, 515-523.
- Muecke, M. (1992b). Nursing research with refugees: A review and guide. *Western Journal of Nursing Research*, 14(6), 703-720.

- Palinkas, L., Pickwell, S., Brandstein, K., Clark, T., Hill, L., Moser, R., et al. (2003). The journey to wellness: Stages of refugee health promotion and disease prevention. *Journal of Immigrant Health*, 5(1), 19-28.
- Pitya, P. (1998). *History of Western Christian Evangelism in the Sudan, 1898-1964*. Boston University, Boston.
- Power, D., & Shandy, J. (1998). Sudanese refugees in a Minnesota family practice clinic. *Family Medicine*, 30(3), 185-189.
- Radda Barnen. (1994). *The unaccompanied minors of Southern Sudan*. Skara: Radda Barnen.
- Raundalen, M., Dyregrov, A., Derib, A., Juma, F., & Kaasa, S. (1994). *A treatment study of the unaccompanied minors from the Southern Sudan*. Nairobi: UNICEF.
- Refugees International. (1999). *Kenya: Violence, kidnapping of women and children at Kakuma*. Retrieved February 2, 2003, from <http://www.refintl.org/content/article/detail/686>
- Refugees International. (2002). *Do not forget the lost girls of Sudan*. Retrieved March 3, 2003, from <http://www.refugeesinternational.org/content/article/detail/788/>
- Renzaho, A. (2004). Fat, rich and beautiful: changing socio-cultural paradigms associated with obesity risk, nutritional status and refugee children from sub-Saharan Africa. *Health Place*, 10(1), 105-113.
- Reynolds, C. C., & Leininger, M. M. (1993). *Madeleine Leininger: Cultural care diversity and universality theory* (Vol. 8). Newbury Park, CA: Sage Publications.
- Richards, L. (2002). *Using N6 in Qualitative Research*. Melbourne, Australia: QSR International Pty. Ltd.
- Robertson, C. L., Halcon, L., Savik, K., Johnson, D., Spring, M., Butcher, J., et al. (2006). Somali and Oromo refugee women: trauma and associated factors. *Journal of Advanced Nursing*, 56(6), 577-587.
- Schechter, J. A. (2004). *Governing "lost boys": Sudanese refugees in a UNHCR Camp*. Unpublished 3136650, University of Colorado at Boulder, United States -- Colorado.
- Seligman, C. G., & Seligman, B. Z. (1932). *Pagan Tribes of the Nilotic Sudan*. London: G. Routledge and Sons.
- Shandy, D. (2001). *Perils and possibilities of Nuer refugee migration to the United States*. Unpublished PhD dissertation, Columbia University, New York.

- Shandy, D. (2002). Nuer Christians in America. *Journal of Refugee Studies*, 15(2), 213.
- Smith, L. (2001). Health of America's Newcomers. *Journal of Community Health Nursing*, 18(1), 53-68.
- Spector, R. (2004). *Cultural Diversity in Health and Illness* (sixth ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- Terrazas, A. (2009). *African Immigrants in the United States*. Retrieved May 2, 2009, 2009, from <http://www.migrationinformation.org/USFocus/display.cfm?ID=719>
- Tompkins, M., Smith, L., Jones, K., & Swindells, S. (2006). HIV Education Needs Among Sudanese Immigrants and Refugees in the Midwestern United States. *AIDS and Behavior*, 10(3), 319-323.
- U.S. Department of State Bureau of Population Refugees and Migration. (2001). *Sudanese (Kakuma) Youth Fact Sheet*. Washington, DC: U.S. Department of State Bureau of Population, Refugees, and Migration.
- UNESCO Institute for Statistics. (2004). *Statistics in brief*. Retrieved September 4, 2006, from [http://www.uis.unesco.org/profiles/EN/EDU/countryProfile\\_en.aspx?code=7360](http://www.uis.unesco.org/profiles/EN/EDU/countryProfile_en.aspx?code=7360)
- UNHCR. (1951). *1951 Convention Relating to the Status of Refugees*. Retrieved May 28, 2005, from <http://www.unhcr.ch/cgi-bin/texis/vtx/protect/opendoc.pdf?tbl=PROTECTION&id=3b66c2aa10>
- UNHCR. (1967). *Protocol Relating to the Status of Refugees of 31 January 1967*. Retrieved June 22, 2005, from [http://www.unhcr.bg/bglaw/en/\\_02\\_protocol%2067en.pdf](http://www.unhcr.bg/bglaw/en/_02_protocol%2067en.pdf)
- United Nations Office for the Coordination of Humanitarian Affairs. (2006a). *The Second Civil War*. Retrieved September 11, 2006, from <http://www.unsudanig.org/sudan/data/history/The%20Second%20Civil%20War.pdf>
- United Nations Office for the Coordination of Humanitarian Affairs. (2006b). *Sudan: The economy*. Retrieved September 13, 2006, from <http://www.unsudanig.org/index.php>
- United States Committee For Refugees. (1999). *Sudan: Personal stories of Sudan's uprooted people*. Washington, DC: Immigration and Refugee Services of America.



- USCRI. (2000). *World refugee survey 2000*. Retrieved August 28, 2005, from <http://www.refugees.org/countryreports.aspx?VIEWSTATE=dDwxMTA1OTA4MTYwOztsPENvdW50cnlERDpHb0JldHRvbjs%2BPrImhOOqDI29eBMz8b04PTi8xjW2&cid=425&subm=&ssm=&map=&ctl0%3ASearchInput=+KEYWORD+SEARCH&CountryDD%3ALocationList=>
- USCRI. (2001). *World refugee survey 2001*. Retrieved February 27, 2002, from <http://www.refugees.org/countryreports.aspx?VIEWSTATE=dDwxMTA1OTA4MTYwOztsPENvdW50cnlERDpHb0JldHRvbjs%2BPrImhOOqDI29eBMz8b04PTi8xjW2&cid=690&subm=&ssm=&map=&ctl0%3ASearchInput=+KEYWORD+SEARCH&CountryDD%3ALocationList=>
- USCRI. (2004). *World refugee survey 2004*. Washington, D.C.
- USCRI. (2005). *Terms and Definitions*. Retrieved June 17, 2005, from <http://www.refugees.org/article.aspx?id=1089>
- USCRI. (2006). *World refugee survey 2006*. Retrieved July 4, 2006, from <http://www.refugees.org/article.aspx?id=1565&subm=19&ssm=29&area=Investigate&>
- USCRI. (2008). *World refugee survey 2008*. Retrieved December 29, 2008, from [http://www.refugees.org/uploadedFiles/Investigate/Publications\\_&Archives/WRSArchives/2008/refugees%20and%20asylum%20seekers%20worldwide.pdf](http://www.refugees.org/uploadedFiles/Investigate/Publications_&Archives/WRSArchives/2008/refugees%20and%20asylum%20seekers%20worldwide.pdf)
- Weaver, H., & Burns, B. (2001). I shout with fear at night. *Journal of Social Work, 1*, 147-164.
- Wehbe-Alamah, H. (2005). *Generic and professional health care beliefs, expressions and practices of Syrian Muslims living in the midwestern United States*. Duquesne University, Pittsburgh.
- Wikipedia Encyclopedia. (2006). *Politics of Sudan*. Retrieved September 11, 2006, from <http://en.wikipedia.org/wiki/Sudan/Government>
- Willis, M. S., & Buck, J. S. (2007). From Sudan to Nebraska: Dinka and Nuer Refugee Diet Dilemmas. *Journal of Nutrition Education and Behavior, 39*(5), 273-280.
- Willis, M. S., & Nkwocha, O. (2006). Health and Related Factors for Sudanese Refugees in Nebraska. *Journal of Immigrant and Minority Health, 8*(1), 19-33.
- Zutt, J. (1994). *Children of war: Wandering alone in southern Sudan*. New York: United Nations Children's Fund.



## Appendix 1

### Leininger's Stranger to Trusted Friend Enabler Guide\*

The purpose of this enable is to facilitate the researcher (or it can be used by a clinician) to move from mainly a distrusted stranger to a trusted friend in order to obtain authentic, credible, and dependable data (or establish favorable relationships as a clinician). The user assesses him or herself by reflecting on the indicators as he/she moves from stranger to friend.

Indicators of Stranger (Largely etic or outsider's views)	Date Noted	Indicators as a Trusted Friend (Largely emic or insider's views)	Date Noted
<p>Informant(s) or people are:</p> <ol style="list-style-type: none"> <li>1. Active to protect self and others. They are "gate keepers" and guard against outside intrusions. Suspicious and questioning.</li> <li>2. Actively watch and are attentive to what researcher does and says. Limited signs of trusting the researcher or stranger.</li> <li>3. Skeptical about the researcher's motives and work. May question how findings will be used by the researcher or stranger.</li> <li>4. Reluctant to share cultural secrets and views as private knowledge. Protective of local lifeways, values, and beliefs. Dislikes probing by the researcher or stranger.</li> <li>5. Uncomfortable to become a friend or to confide in stranger. May come late, be absent and withdraw at times from researcher.</li> <li>6. Tends to offer inaccurate data. Modifies "truths" to protect self, family, community, and cultural lifeways. <i>Emic</i> values, beliefs, and practices are not shared spontaneously.</li> </ol>		<p>Informant(s) or people are:</p> <ol style="list-style-type: none"> <li>1. Less active to protect self. More trusting of researchers (their "gate keeping is down or less"). Less suspicious and less questioning of researcher.</li> <li>2. Less watching the researcher's words and actions. More signs of trusting and accepting a new friend.</li> <li>3. Less questioning of the researcher's motives, work and behavior. Signs of working with and helping the researcher as a friend.</li> <li>4. Willing to share cultural secrets and private world information and experiences. Offers most local views, values and interpretations spontaneously or without probes.</li> <li>5. Signs of being comfortable and enjoying friends and a sharing relationship. Gives presence, on time, and gives evidence of being a "genuine friend."</li> <li>5. Wants research "truths" to be accurate regarding beliefs, people, values and lifeways. Explains and interprets <i>emic</i> ideas so researcher has accurate data.</li> </ol>	

\* Developed and used since 1959: Leininger  
 From *Culture Care Diversity & Universality*, by M. Leininger, 1991, New York: National League for Nursing Press.

## Appendix 2

Open Inquiry Guide for Discovering Culture Care Beliefs, Meanings and Practice Related to Health and Well-Being	
ETHNODEMOGRAPHICS	
Informant #:	Year of Birth:
Gender:	Marital Status:
Tribal and Clan Affiliation:	Religion:
Languages Spoken:	Children:
Education:	Refugee camps:
OPEN-ENDED QUESTIONS	
Environmental Context	Kinship & Social Factors
<p>Can you tell me about where you were born?</p> <p>Can you tell me about your childhood before the war?</p> <p>What would you like me to understand about your journey from home until your arrival at Kakuma?</p> <p>Can you tell me about your life at Kakuma?</p> <p>Is there anything you would like me to know about your environment in Africa, where and how you lived, and how it relates to your health and well-being?</p> <p>Tell me about coming to the United States</p> <p>Describe how your life has been different or the same since you came to the United States.</p> <p>Who lives with you in your household?</p> <p>Is there anything you would like me to know about your environment now, where and how you live, and how it relates to your health and well-being?</p>	<p>Can you tell me about your ancestors as far back as you can remember? What role do ancestors have in life today?</p> <p>What is the main responsibility of the male or husband in your culture? Female or wife?</p> <p>Who makes the important decisions within your culture? Your family? Who is consulted?</p> <p>What is the significance of marriage in your culture? How are spouses chosen and marriages arranged? Who is consulted? What is required of the man prior to marriage? The woman?</p> <p>In what ways is your marriage traditional? In what ways not? If not married, how do you anticipate choosing a spouse and arranging a marriage? Who will you consult?</p> <p>How are divorce and/or separation handled in your culture? Is divorce accepted? What happens to the children? The wife? The husband?</p> <p>How are children raised in your culture? What is expected of them? How are they taught/disciplined? What responsibilities do you have for your family in Africa? Your family here in the United States?</p>
Cultural Values & Lifeways	Worldview/Religious & Spiritual Factors
<p>What specific values and beliefs do you have that would identify you as Dinka/Nuer?</p> <p>What values and beliefs related to your culture will be most important for you to pass on to your children?</p>	<p>What does your religion mean to you?</p> <p>Which religious rituals or ceremonies do you observe?</p> <p>Can you tell me the relationship between religious/spiritual beliefs and health and well-being?</p> <p>Tell me about any religious traditions you follow when sick.</p> <p>Are there certain views of what or who influences illness in your culture?</p> <p>Who do you turn to for spiritual support?</p> <p>Are there any foods that you eat or avoid based on your religious beliefs?</p>

<b>Economic Factors</b>	<b>Political &amp; Legal Factors</b>
<p>Tell me about your work here in the United States. What are your financial responsibilities, both here and back home?</p> <p>Do you have any worries about your economic situation?</p> <p>Who do you turn to when you need financial assistance?</p> <p>How does your economic situation impact your health and well-being?</p> <p>How do you pay for health care?</p> <p>Does your economic situation have any impact on where, when or from whom you seek health care?</p>	<p>Tell me about the political situation in Sudan now. What effect does the political situation there have on your life here?</p> <p>Is there any relationship between the political situation in Sudan and your health and well-being?</p> <p>Who are the most influential leaders in your community in Sudan?</p> <p>Who are the most influential leaders in your community here?</p> <p>How do their actions impact your health and well-being?</p>
<b>Educational Factors</b>	<b>Technological Factors</b>
<p>Tell me about the significance of education in your life.</p> <p>What are your educational goals?</p> <p>Are there any obstacles that make it difficult to reach those goals?</p> <p>Does education have any impact on your health and well-being?</p>	<p>How does technology influence your way of life?</p> <p>Does technology have any impact on your health and well-being?</p>
<b>Health and Well-Being</b>	
<p>Describe for me what health means to you. Illness?</p> <p>Can you tell me what you do to stay healthy? Things that you avoid doing?</p> <p>Can you tell me how illnesses can be prevented, diagnosed, or treated in your culture?</p> <p>What kinds of things could a nurse do to promote your health?</p> <p>Tell me about any people available in your community who can assist you to stay well or treat your illnesses.</p> <p>Tell me some words that describe well-being for you.</p> <p>What do you do to maintain a sense of well-being?</p> <p>Tell me about any healthful practices you do now that differ from those you did in Sudan or Kakuma.</p> <p>What are some things that nurses need to know about your people that would help the people to be healthy?</p> <p>Who do you turn to when you have concerns about your health?</p> <p>What role do you have in helping others maintain their health and well-being?</p>	
<b>Care Expressions, Patterns &amp; Practices</b>	
<p>Describe what care means to you.</p> <p>Can you give me some words which describe a caring person? A non-caring person?</p> <p>Have you ever received care from a healer in your community? In what ways do they show care?</p> <p>Tell me about the care you receive from family or friends. In what ways do they show care?</p> <p>Have you ever received care from a nurse in the community? In what ways do they show care?</p> <p>Can you give me some examples of care you've received in a hospital or clinic?</p> <p>If you have a sick friend, what would you do to care for him/her?</p> <p>If in the future, you are admitted to a hospital, what things would you like the nurse to do to show care?</p>	
<b>Closure</b>	
<p>We've had a wonderful opportunity to talk about health, well-being and caring. Is there anything else that you would like to tell me? Is there anything else that you would like to know from me?</p>	

## Appendix 3



600 FORBES AVENUE  
PITTSBURGH, PA 15282  
TEL 412.396.6550  
FAX 412.396.6346  
www.nursing.duq.edu

### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

- TITLE:** Culture Care Beliefs, Meanings and Practices Related to Health and Well-Being of Sudanese “Lost Boy and Lost Girl” Refugees
- INVESTIGATOR:** Margaret Bowles RN MSN  
268 Morris Avenue SE  
Grand Rapids, MI 49503
- ADVISOR:** Rick Zoucha, APRN, DNS, CTN  
Duquesne University School of Nursing  
521 Fisher Hall  
Pittsburgh, PA 15282
- SOURCE OF SUPPORT:** This study is supported by a grant from the Transcultural Nursing Society
- PURPOSE:** You are being asked to participate in a research study that seeks to investigate the health care beliefs, meanings and practices of Sudanese lost boys and girls now living in the United States. I will be asking you to allow me to interview you between one and three times. Each interview will take about 1 or 2 hours. During these interviews I will be asking about your cultural beliefs and practices and their meanings related to health, well-being and caring. The interviews will be tape recorded and then written down so that I can study and learn from what you have said.
- RISKS AND BENEFITS:** I do not know of any risks or direct benefits to you as a participant in this study. However, should you become distressed during the study and require an intervention; a psychiatric mental-health clinical nurse specialist will be available for consultation. Changes may occur in patient care for Sudanese lost boys and girls in the United States, and in nursing education regarding the care needs of the lost boys and girls, after the study is completed.

Education for the Mind, the Heart, and the Soul

**COMPENSATION:** You will not be paid for participating in this study, nor will it cost you anything to participate.

**CONFIDENTIALITY:** Your name will never appear on any survey or research instrument used for this study. The person who will assist in transcribing the tapes will sign a confidentiality agreement and will not have access to your name. When the audiotapes are transcribed, all identifying information about you or anyone you talk about will be deleted. No identity will be made in the data analysis. Your response(s) may appear as de-identified quotes in summaries of findings and in reports of the data presented in publications and/or presentations. De-identified quotes may also be shared with members of my dissertation committee. All written materials, consent forms, and tapes used in this study will be stored in a locked file in my home and will be destroyed when all activities related to the study are completed.

**RIGHT TO WITHDRAW:** You do not have to talk to me or participate in this study. I will understand if this is your wish. If you do not want to answer a question, just say so and we will skip that question. You are free to withdraw your consent to participate at any time.

**SUMMARY OF RESULTS:** A summary of the results of this research will be supplied to you, at no cost, upon request.

**VOLUNTARY CONSENT:** I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reasons. On these terms, I certify that I am willing to participate in this research study.

I understand that should I have any further questions about my participation in this study, I may call Dr. Paul Richer, Chair of the Duquesne University Institutional Review Board (412)-396-6326) or Dr. Rick Zoucha at 412-396-6545 or Margaret Bowles at 616-459-2356. I will be given an opportunity to discuss, in confidence, any questions with any member of the Institutional Review Board.

---

Participant's Signature

---

Date

---

Researcher's Signature

---

Date

## Appendix 4

### CONFIDENTIALITY STATEMENT

I understand that as a transcriptionist for a study being conducted by Margaret Bowles, a doctoral student at Duquesne University, under the supervision of Dr. Rick Zoucha, I am privy to confidential information. I agree to keep all data collected during this study confidential and will not reveal it to anyone outside the research team. I will return all documentation and audiotapes to Margaret Bowles and delete the original transcriptions from the hard drives of my computer whenever she instructs me to.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Witness Signature: \_\_\_\_\_

## APPENDIX 5

### Leininger's Phases of Ethnonursing Analysis for Qualitative Data\*

#### Fourth Phase

*Major themes, research findings, theoretical formulations, and recommendations.*

This is the highest phase of data analysis, synthesis, and interpretation. It requires synthesis of thinking, configuration analysis, interpreting findings, and creative formulation from data of the previous phases. The researcher's task is to abstract and present major themes, research findings, recommendations, and sometimes theoretical formulations.

#### Third Phase

*Pattern and contextual analysis.* Data are scrutinized to discover saturation ideas and recurrent patterns of similar or different meanings, expressions, structural forms, interpretations, or explanations of data related to the domain of inquiry. Data are also examined to show patterning with respect to meanings-in-context along with further credibility and confirmation of findings.

#### Second Phase

*Identification and categorization of descriptors and components.* Data are coded and classified related to the domain or inquiry and sometimes the questions under study. *Emic* or *etic* descriptors are studied within context and for similarities and differences. Recurrent components are studied for their meanings.

#### First Phase

*Collecting, describing, and documenting raw data (use of field journal and computer).* The researcher collects, describes, records, and begins to analyze data related

to the purposes, domain of inquiry, or questions under study. This phase includes: recording interview data from *key* and *general* informants; making observations, and having participatory experiences; identifying contextual meanings; making preliminary interpretations; identifying symbols; and recording data related to the phenomenon under study, mainly from an *emic* focus, but attentive to *etic* ideas. Field data from the condensed and full field journal is processed directly into the computer code.

\* Leininger, M. M. (1987, 1990, and current revisions in 1991).

From *Culture Care Diversity & Universality*, by M. Leininger, 1991, New York: National League for Nursing Press.